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FEASIBILITY OF TYPE 2 DIABETES PREVENTION

PROCESSES FOR DETECTION, SELF-MANAGEMENT AND SUPPORT IN SOCIOECONOMICALLY DISADVANTAGED AREAS

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Feasibility of type 2 diabetes prevention: Processes for detection, self-management and support in socioeconomically disadvantaged areas

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POPULAR SCIENCE SUMMARY

Diabetes is a global health threat unequally affecting lower socioeconomic groups to a higher degree. Type 2 diabetes (T2D) is the most common form of diabetes. Prediabetes is a condition where blood sugar levels are highly elevated, but not yet diabetic. By making lifestyle changes, improving diet and increasing physical activity, the elevated blood sugar levels can be lowered. Yet many people with prediabetes or T2D are undiagnosed or unaware about their risk of developing diabetes. Screening for diabetes is one way to detect and prevent diabetes for avoiding complications caused by elevated blood sugar levels. Screening results can lead to people becoming aware of their health status in relation to diabetes and make the changes needed for good health. Lifestyle interventions with self-management support improve both the physical and mental health of people with T2D and those at risk of developing diabetes. Telephone coaching is a support approach that has proven to be effective, especially for people with lower socio-economic status.

Within the scope of this thesis we want to find out how people relate to the risk of developing diabetes and lifestyle changes due to diabetes risk. We compare community screening to screening at health care centers and examine to what extent a telephone-based health intervention implemented in socio-economically disadvantaged areas for people with T2D and at high risk of developing diabetes is acceptable. Dimensions of interaction between the health coach and the participant during the sessions are also rated and investigated.

Study 1 based on interviews with persons at risk of developing T2D reveals that the risk of diabetes is not frightening enough to justify lifestyle changes and that something external, such as a diagnosis where dietary changes are required, motivate change. A partner's diagnosis also had an impact on a couple's daily routine. From study 2 we learn that screening in the local community reached foreign-born people from Africa and Asia as well as younger people to a greater extent, while health centers screened more persons born in Sweden and other European countries. Women participated in both screenings more frequently than men. Study 3 suggests that the telephone-based health intervention is an acceptable approach. However, participation was considered more burdensome for younger persons at risk of developing diabetes. Study 4 pointed out differences in how health coaches delivered coaching sessions, in particularly when setting goals for lifestyle changes. The importance of tailoring the program to participant needs was emphasized and language competence was sometimes problematic in the communication.

In summary, motivating people at high risk of developing diabetes is a challenge as the risk of diabetes is not seen as a reason for lifestyle changes and participation in a lifestyle intervention seems more burdensome for this group. Also, both community screening and screening at health facilities are needed to reach different population groups. Support in the form of telephone coaching to promote healthy lifestyle habits works well in socioeconomically disadvantaged areas and language is an important aspect in the delivery of health coaching sessions.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Diabetes är ett globalt hälsoproblem som drabbar lägre samhällsklasser i högre grad. Typ 2 diabetes (T2D) är den vanligaste formen av diabetes. Många människor med T2D är odiagnostiserade eller ovetande om sin diabetesrisk. Prediabetes är ett tillstånd där blodsockervärdena är kraftigt förhöjda men ännu inte så höga som vid diabetes. Genom livsstilsförändringar, såsom förbättrade matvanor och ökad fysisk aktivitet, kan förhöjda blodsockervärden sänkas till normala nivåer.

Diabetesscreening är ett sätt att upptäcka och förebygga diabetes för att undvika komplikationer orsakade av förhöjda sockervärden. Screeningresultaten kan göra personer medvetna om sin hälsostatus i förhållande till diabetes och få dem att vidta åtgärder som behövs för en god hälsa. Livsstilsinterventioner med support för egenvård har visat sig effektiva för att förbättra både fysisk och mental hälsa för personer i riskzonen för att utveckla diabetes och personer med T2D. Telefoncoaching är en form av support som visat sig vara effektiv, särskilt för personer med lägre socioekonomisk status.

Inom ramen för denna avhandling tar vi reda på hur personer förhåller sig till risken att utveckla diabetes samt till livsstilsförändringar med anledning av diabetesrisk. I en jämförelse av screening i lokalsamhällen och på vårdcentraler, undersöker vi vilka personer som nås av olika typer av diabetesscreening. Vi tar även reda på till vilken grad en telefonbaserad hälsointervention som implementerats i socioekonomiskt utsatta områden är acceptabel, samt ser närmare på interaktionen mellan hälsocoachen och deltagaren under hälsosamtalen.

I studie 1 framgick det att diabetesrisk inte ses som tillräckligt skrämmande för att motivera livsstilsförändringar, utan att något ytterligare behövs, exempelvis en diagnos där förändrade matvanor krävs. Även en partners diagnos visade sig påverka matvanorna. Från studie 2 kunde vi se att screening i lokalsamhället nådde utrikesfödda personer från Afrika och Asien till en högre grad, medan vårdcentralerna screenade fler personer födda i Sverige och andra europeiska länder. Lokalsamhällesscreening lockade även fler yngre personer. Fler kvinnor än män deltog i båda formerna av screening. Studie 3 visade att den telefonbaserade hälsointerventionen var en accepterad interventionsform, medan deltagandet i interventionen ansågs något mer ansträngande för yngre personer med risk för att utveckla diabetes. Studie 4 påvisade skillnader mellan coacherna bland annat vad det gäller att sätta mål för livsstilsförändringar. Bristande språklig kompetens kunde utgöra ett hinder för en optimal kommunikation och vikten av att skräddarsy programmet för att leva upp till deltagarens behov betonades.

Sammanfattningsvis behövs olika typer av diabetesscreening. Support i form av telefoncoaching för att främja hälsosamma livsstilsvanor fungerar bra i socioekonomiskt utsatta områden. Att motivera personer med hög risk för att utveckla diabetes till att göra livsstilsförändringar är en utmaning, eftersom att diabetesrisk inte ses som en anledning till att göra förändringar, samt att deltagandet i en livsstilsintervention tycks vara mer ansträngande för denna grupp.

ABSTRACT

Background: Type 2 diabetes (T2D) is on the rise globally, affecting disadvantaged populations to a higher extent. Both T2D and prediabetes are often undiagnosed. Early detection of T2D and prediabetes is of importance to avoid complications due to metabolic disturbances caused by elevated glucose values. Self-management support and lifestyle interventions to manage and prevent diabetes have proven to be effective strategies in high income settings.

Aim: To determine the feasibility of early detection and implementation of a self-management support intervention for T2D and persons at risk in socioeconomically disadvantaged areas in Stockholm.

Methods: Mixed methods were utilized. In study 1, 15 qualitative interviews were conducted with persons living with a high risk of developing diabetes over a period of ten years. The data were analyzed using qualitative content analysis. Study 2 compared data from community screening and facility-based screening generated from 2,564 participants to investigate screening reach using descriptive statistics. In study 3 a tool was developed to assess participant satisfaction of a telephone-facilitated health coaching intervention. Study 4 consisted of testing a tool to understand different dimensions of interaction between facilitators and participants in the health coaching intervention. Interaction scoring was performed and thematic analysis applied on quality assurance meetings with facilitators. Exploratory factor analyses were conducted for both study 3 and study 4 for tool development and interpretation of results.

Results: The main theme developed from the qualitative interviews was that the risk of T2D is not concrete enough to motivate lifestyle modification without other external triggers. Persons born in Africa and Asia were reached to a higher extent through community screening, while persons born in Sweden and other European countries were reached more through facility-based screening. Participants reported the health coaching intervention as acceptable, although the perceived burden was higher among younger individuals and those at high risk compared to participants with T2D. Differences in coaching styles were found between facilitators in intervention delivery, particularly in goal setting, and limitations in language skills were a hinder in the communication between facilitators and participants.

Conclusions: The potential of reversing diabetes and prediabetes should be highlighted and more clearly defined to serve as motivators for lifestyle modification. Community- and facility-based screening are complementary methods in reaching people at high risk. Telephone-facilitated health coaching is an acceptable support intervention in socioeconomically disadvantaged population groups and should be considered when planning prevention and management strategies. Tailoring the intervention to meet participant needs is important and language skilled facilitators are needed to reduce hinders in intervention delivery.

LIST OF SCIENTIFIC PAPERS

I. **Timm L**, Daivadanam M, Lager A, Forsberg B, Östenson CG, Mölsted Alvesson H. "I Did Not Believe You Could Get Better" - Reversal of Diabetes Risk Through Dietary Changes in Older Persons with Prediabetes in Region Stockholm. Nutrients. 2019;11(11): 2658. DOI: 10.3390/nu11112658.

II. **Timm L**, Harcke K, Karlsson I, Sidney Annerstedt K, Alvesson HM, Stattin NS, Forsberg BC, Östenson CG, Daivadanam M. Early detection of type 2 diabetes in socioeconomically disadvantaged areas in Stockholm - Comparing reach of community and facility-based screening. Global health action. 2020;13(1):1795439. DOI: 10.1080/16549716.2020.1795439.

III. **Timm L**, Sidney Annerstedt K, Álvarez Ahlgren J, Absetz P, Alvesson HM, Forsberg BC, Daivadanam M, Application of the Theoretical Framework of Acceptability to assess a telephone-facilitated health coaching intervention for the prevention and management of type 2 diabetes.
[Submitted manuscript].

IV. **Timm L**, Karlsson I, Sidney Annerstedt K, Absetz P, Forsberg BC, Daivadanam M, Alvesson HM. Understanding dimensions of interaction between participants and facilitators in a telephone-facilitated health coaching intervention for diabetes care and prevention.
[Manuscript].

CONTENTS

LIST OF ABBREVIATIONS

ADA	American Diabetes Association
BMI	Body Mass Index
CCM	Chronic Care Model
CNI	The Care Need Index
CVD	Cardiovascular disease
ECCM	The Expanded Chronic Care Model
FPG	Fasting plasma glucose
FINDRISC	The Finnish diabetes risk score
4D	Four diagnoses
GDPR	General Data Protection Regulation
HbA1c	Glycosylated haemoglobin A1c
HL	Health literacy
NCD	Non-communicable disease
NGO	Non-governmental organization
PHC	Primary health care
PHCC	Primary health care center
RCT	Randomised control trial
REDCap	Research electronic data capture
SDPP	Stockholm Diabetes Prevention Program
SCB	Statistics Sweden (Statistiska centralbyrån)
SMART2D	Self-Management and Reciprocal learning for Type 2 Diabetes
SES	Socioeconomic status
TFA	Theoretical Framework of Acceptability
T2D	Type 2 diabetes
WHO	World Health Organization

1 PREFACE

This doctoral project is nested in the EU project Self-management approach and reciprocal learning for type 2 diabetes (SMART2D), implemented in Sweden, South Africa and Uganda. The rise of diabetes prevalence is a global concern, which I have studied in a local context in socioeconomically disadvantaged areas in Stockholm both as a PhD student and by working as an implementation manager for SMART2D from August 2016 to December 2019 when the project closed. Initially, the work consisted of planning and arranging community screening. I took part in the development of information material such as brochures, roll-up posters and flags and ordered material needed for the fieldwork. As an implementation manager I had contact with primary health care centers, citizens' service offices and local organizations in the study sites. In the process of collaboration between stakeholders and SMART2D, my role also included becoming the communication channel between them. In practice this meant that I often travelled to these suburbs with the subway with my 'mobile office' consisting of laptop and files that I carried in a roller bag, meeting people living and working in these local communities. I worked closely with diabetes nurses from the primary health care centers in the study sites and learned a lot about how it is to work in disadvantaged settings and the everyday challenges they meet in their work with diabetes patients. Although familiar with my hometown Stockholm, these suburbs differed from my neighborhood in terms of socioeconomic circumstances.

During the community screening period I spent even more time in the two study areas conducting screening tests and recruiting participants to the SMART2D project. In the implementation phase of the intervention I worked to contextualize the peer support format together with the SMART2D team. I had an active role in pilot-testing peer groups for diabetes prevention and management. The peer group format turned out to not be feasible in these communities and instead an individualized telephone-facilitated health coaching support was developed and implemented. Although the pilot phase with peer groups did not succeed, these were valuable opportunities for me to interact with the people living in the communities and all these experiences have built on my understanding of the challenges of prevention in this study context.

I also had the opportunity to visit my colleagues in Cape Town, South Africa to gain insights on their work and the collaboration with community health workers, which deepened my understanding on diabetes prevention and management in a broader context. A visit to Uganda was also planned, but this was unfortunately cancelled due to the coronavirus pandemic. Many of the people I have met through spending time in the field have shared stories from their everyday lives that I carry with me. Their stories will forever remind me of the social determinants and inequities related to health, that are of great importance when working to improve health outcomes for persons living in socioeconomically disadvantaged areas.

2 INTRODUCTION

TYPE 2 DIABETES AND PREDIABETES

The prevention of diabetes is crucial for hindering the global increase in prevalence. The current diabetes prevalence is 9.3% globally [1]. According to World Health Organization (WHO) the diabetes prevalence is projected to increase by 50% from 2014 to 2024 and to be the seventh leading cause of death by 2030 [2]. Diabetes is one of the non-communicable diseases (NCDs) that is stated in the Sustainable Development Goals (SDGs) call to action. Type 2 diabetes (T2D) is the most common form of diabetes affecting disadvantaged populations disproportionately depending on socioeconomic circumstances [3-10]. Approximately 50% of persons living with diabetes are estimated to be undiagnosed [1]. In addition, many persons are at high risk of developing diabetes or having prediabetes. Prediabetes is an established high-risk state of T2D where the glucose levels are elevated but not yet considered diabetic [11]. As such, it is a serious health condition but not a diagnosis and its global prevalence is estimated to be 7.5% [1]. High risk of diabetes can be determined by different risk assessment tools measuring risk factors [12], where certain cut-off points are set to define persons at high risk of developing diabetes. [1, 13]. Early detection of T2D and prediabetes has the potential to reduce undiagnosed diabetes and prevent complications such as cardiovascular disease (CVD) [14, 15].

Risk of developing diabetes and the potential of reversibility

T2D risk is the result of an interplay between genetic and metabolic factors. Modern lives with high energy intakes combined with low physical activity levels and high levels of psychosocial stress and tobacco use contribute to metabolic disorders like T2D [16]. Although diabetes risk is partly determined by genes, there are studies showing that "modifiable factors relating to body weight, diet, and physical activity are more likely to impact on glycemic traits than genetic predisposition during a behavioral intervention" [17].

Low socioeconomic status, social suffering and stress are associated with the development of T2D and demonstrate a social gradient in T2D prevalence [3-10, 18]. In addition to individual characteristics such as educational level, occupation and income, community characteristics in terms of access to healthy foods and healthcare influence the development of T2D [18]. Low education often means low income and higher risk of unemployment, factors that can influence food choices leading to overweight [4, 7]. Obesity is a major risk factor and weight reduction through lifestyle modification in terms of increased physical activity levels and changing to healthier diets are effective [2, 19]. The most common focus in lifestyle interventions is change in body weight as an outcome [20], although other risk factors such as stress and tobacco smoking are also associated with diabetes. The prevention of T2D is highly dependent on

lifestyle modification, but the ones affected by T2D are often persons with low lifestyle choices [21]. Obesity is a stigmatized condition associated with diabetes [22].

The diagnosis of diabetes and prediabetes is mostly established by fasting plasma glucose (FPG) tests or glycosylated hemoglobin A1c (HbA1c) tests. The global cut-off for T2D is FPG of ≥7 mmol/l or HbA1c of ≥48 mmol/l [23]. According to the American Diabetes Association (ADA), prediabetes ranges from FPG of 5.5 to 6.9 mmol/l or HbA1c of 42-47 mmol/l [23], although other cut-offs have been used. Prediabetes is recognized as a reversible condition with the potential to normalize glucose levels through lifestyle modification [24, 25]. The reversibility of T2D [26, 27] however, has been a subject of debate in medical circles. While the diagnosis is permanent, research shows that T2D remission can be achieved through dramatic weight reduction [28, 29]. Weight reduction leading to T2D remission has been reported as a result of intensive lifestyle modification interventions that include dietary changes [28, 30, 31] and after bariatric surgery followed by dietary restrictions [32, 33]. It has been described that T2D reversal remains possible for at least 10 years after its onset [26].

Prediabetes can be asymptomatic, although the glucose values are highly elevated, but the complications such as CVD and retinopathy can start already in the prediabetes phase [14, 34]. From this perspective, there are advantages in early diagnosis and treatment for persons at high risk of developing diabetes. Prediabetes can also be seen as an overdiagnosis leading to medicalization [35] and prognostic uncertainty [36]. The ADA's Expert Committee reduced the threshold for impaired fasting glucose from 6.1 mmol/L (110 mg/dL) to 5.6 mmol/L (100 mg/dL) for diagnosing persons with prediabetes in 2003 [37], and it can be argued that it can lead to medicalization and an unsustainable burden on healthcare at a systemic level [35]. Major consequences of overdiagnosis at an individual level are the anxiety and reduced quality of life due to an unnecessary diagnosis and the cost and harm due to unnecessary treatment [38].

Screening for early detection of T2D and diabetes risk

Different prevention strategies are needed to decrease the global burden of T2D and its complications. Diabetes screening is a strategy for early detection of persons at risk of and with unknown T2D. There are mainly two types of screenings used for T2D; opportunistic screening conducted at health facilities where people seek care for other health related reasons and community screenings outside ordinary healthcare environments. Opportunistic screening is recommended to detect persons at high risk of developing diabetes [39, 40]. At the same time it only targets patients who actively seek care, while community screening has the potential to reach persons who do not seek care actively in health facilities [41, 42]. Community screening has been shown to be effective in reaching high risk individuals [43, 44]. Screening should only be conducted in settings where resources are available for further treatment and management of the disease or risk state [45]. Community screening was found to be more accessible, convenient and free from cost for participants in a semirural community in Texas, United States, while cost of further tests or treatment, fear of disease and lack of time were seen

as barriers [46]. There is some indication that individuals detected through T2D screening are diagnosed earlier than when clinically detected [47] and that they have a lower all-cause mortality, CVD and damage to the kidneys and eyes [47]. There is only limited support for population-wide universal T2D screening where all persons in a certain category are screened due to its low effect in reducing CVD incidence and mortality [48], which does not make it a cost-effective strategy on its own. However, screening for diabetes in tandem with other screening initiatives such as blood pressure screenings is effective and a more cost-effective alternative [49].

Tools and measures used for T2D screening are not uniform. Risk assessment questionnaires followed by a blood test are a common diabetes screening method. [12]. To predict future diabetes risk, questions about family history of diabetes and health behavior (diet, physical activity) have been found to be feasible to administer in primary care [50]. To detect persons at high risk of developing diabetes, risk assessment tools such as the Finnish diabetes risk score (FINDRISC) have been widely used in both facility-based screenings and community screenings [51-54]. FINDRISC is validated tool that has been used in multiple contexts and target groups [51-54]. It consists of eight questions and a scoring systems ranging from 1 to 5, recognized as an effective, simple and non-invasive tool to identify high-risk individuals [45, 55] (Table 1).

Table 1. Variables and maximum scores achieved from the Finnish diabetes risk score (FINDRISC)

Variables	Max score
Age	4
BMI	3
Waist	4
Physical activity 30 min/day	2
Intake of vegetables or fruit every day	1
Medication for high blood pressure	2
Elevated glucose values earlier in life	5
Family history of diabetes	5

FINDRISC is commonly followed by blood glucose measurements using FGT, HbA1c or oral glucose tolerance tests. A multi-step approach where two different screening methods are used serially, increases the diagnostic yield and decreases the number of persons having to undergo a blood test [56]. HbA1c tests have been found to be a better glucose measurement than random glucose for both undetected diabetes and cardiovascular risk [57], but HbA1c tests have been criticized as being inefficient in detecting prediabetes as they are limited by ethnic, racial and gender differences [58, 59]. A literature review concluded that HbA1c was neither sensitive nor specific for detecting prediabetes and that fasting glucose was specific but not sufficiently sensitive [60]. Therefore, different screening methods can lead to varying degrees of false positive or negative tests leading to incorrect diagnosis or mis-diagnosis [60]. Moreover,

logistics around screening related to the venue for screening, i.e., primary care or facility versus a community site, would also influence the type of screening method used.

Risk communication

Risk communication is central in prevention of NCDs such as T2D and it is important for self-management. To communicate risk can be complicated since risk is an interplay between feelings and rational understanding [61]. By receiving risk information, people get more informed and aware of their risk status and gain the opportunity to act on their condition [62] and reduce their diabetes risk. On the other hand, there are examples of risk information leading to experiences of illness and talking about disease, diagnosis and risks may in themselves cause psychosomatic symptoms and anxiety [63, 64]. From this perspective risk information can cause harm to individuals if it is seen as "sickening" [65]. Similarly, to know about risks can lead to shaping the identity of a sufferer [64].

Problems in health provider-patient communication are very common and affect patients' management of their disease. Patients with low socioeconomic status (SES) were found to be in a disadvantaged position during a medical consultation, both because the providers misinterpret their need and desire for information and the patients have a more passive communication style compared with those from higher SES groups [66]. Poor communication correlates with medical mistrust in low-income diabetes patients in high-income countries [67] and has shown to lead to higher glucose values [68]. The provider-patient communication is reciprocal and interactive [69] and it has been shown that both providers' communication skills [69] as well as the patients' communication skills [70] would benefit from improvements.

There is a diversity in how patients communicate and the levels of health literacy (HL) among diabetes patients. Lower HL is associated with less knowledge of diabetes leading to poorer self-management and glucose monitoring [71]. An important factor for self-management of T2D related to dietary recommendations is to have functional HL in terms of basic reading and writing skills applied for health [72]. Independent of the HL level, diabetes management education has been found to be beneficial [73]. According to one study, patients with low HL had more mistrust in their health providers and perceived less involvement in their diabetes care compared to patients with high HL, which worsened in patients with longer disease duration [67]. In addition, low HL levels are associated with limited utilization of medical technology [74]. Numeracy skills are also important for diabetes patients, where complex numerical data are received for the management of disease that can be beyond their capacity to follow and understand [75]. Translating technical terms into lay language is recommended [76]. Since language is an important aspect in the provider-patient communication, close work with interpreters can be needed. However, translated information is not always exact, for instance when relatives are used as interpreters [76].

Lifestyle interventions in disadvantaged settings

Different population groups have been described as disadvantaged, such as persons with low SES, ethnic and sexual minorities, culturally diverse populations, indigenous groups and marginalized groups such as people with disabilities and homeless people [77]. These populations groups are in general economically poor, with worse health and with lower access to health services [78].

Lifestyle interventions, including elements of habitual change can be particularly challenging in socioeconomically disadvantaged populations [79], although positive effects of lifestyle interventions have been found in those population groups [80, 81]. Positive effects have been shown in reducing the rate of metabolic syndrome, which is one of the strongest predictors of T2D and CVD [80]. Lifestyle interventions also reduce anxiety, stress and depression in socioeconomically disadvantaged women [80]. Another positive effect of diabetes programs was an improvement in women's use of and access to community preventive services [81].

Cost and lack of time have been reported as reasons for poorer dietary behavior in women with low SES [82]. Many women also did not prioritize their food choices in comparison with other family members' needs and reported on challenges in managing self-care and maintaining the active role with family responsibilities [82, 83]. Moreover, some women avoided to talk about their condition to avoid worrying others and also used it as a strategy to protect themselves from being treated like patients [83]. Traditions and family practices were valued more in the participants with low SES compared to women of higher SES [82], which could be an explanation for not changing dietary habits easily. Lifestyle interventions also risk blaming individuals for poor health outcomes instead of focusing on structural problems [21, 84-86]. Persons with T2D report on being subject to negative stereotyping, feeling blamed by others and having restricted opportunities in life [22]. They also experience negative attitudes and a focus on failure from health providers when not managing losing weight [22]. A literature review of lifestyle interventions in 19 randomised control trials (RCTs) showed that all studies included had changes in body weight as an outcome [20]. The review concluded that obesity was seen as a dangerous risk burden and therefore weight loss was necessary [20].

There are a variety of support approaches that have proven effective for diabetes self-management. Examples include face-to-face meetings held with health care personnel or peers in group format [87], individual support offered by health care providers or personal health coaches [88], support provided by community health workers [89], web- and email-based support [90] and telephone-based support by peers and health professionals offered [91]. A literature review on telephone coaching found this strategy in particularly beneficial to persons who had worse control of their chronic conditions at baseline and with low access to health services [91].

Intercultural health care

Culture is a non-static process through which activities and conditions take on a moral meaning for the participant [92]. Cultural processes differ within the same social or ethnic groups according to aspects such as age, gender, class, religion and also personality [92]. Moreover, cultural belonging of a patient can change [92, 93]. In multicultural healthcare settings there is a diversity among patients in terms of languages spoken, expectations on health care and cultural models of disease, which is the case of Swedish health care. In addition, the healthcare personnel themselves often have a diverse or foreign background.

Beliefs about health related to diabetes can differ by ethnicity [94, 95]. One example is that experiences from migration can be seen as an explanation for T2D development in immigrant populations in Sweden [94]. Therefore, intercultural health care is a relevant concept for studies in these settings [96]. In implementation and other real-life trials the target population often tends to be heterogeneous, thereby increasing the complexity of intervention delivery and communication.

Culture has been seen a hindrance or an excuse for understanding and communication within healthcare, leading to: discrimination due to foreign origin [97]; a predominance of negative experiences in care settings [98]; stereotyping of patients [92, 93] and assumptions leading to group-based discrimination [93]. Moreover, it appears to be easier to think of other people as being culturally influenced than oneself. There is also a risk conserving structural power imbalances by maintaining such discourses on culture [99].

Not having the right tools and skills to interact with people with different cultural backgrounds has been shown to cause stress and anxiety among health providers [96]. Intercultural competence in terms of attitudes, skills, knowledge and competence, is increasingly being recognized as essential for healthcare training and practice in order to communicate effectively and appropriately with an increasingly diverse target population [100, 101]. At the same time, the use of guidelines for cultural competence in multi-ethnic care settings have been found challenging when the group of patients is very diverse and persons do not fit into the predefined cultural categories [93]. Cultural competence does not only apply to health providers, but also to patients who need to be able to navigate in the health care systems [76]. Educational training interventions in intercultural competence for health providers have proved effective for improving health communication [102].

THEORETICAL BASIS OF DIABETES PREVENTION

The Expanded Chronic Care Model (ECCM)

The chronic care model (CCM) [103] is an organizational approach for caring of people with chronic diseases and it is one of the most widely used models to understand healthcare practices and health outcomes within primary healthcare for chronic diseases including diabetes [104, 105] and showing positive clinical outcomes for diabetes patients [105].

An expanded version of the CCM, known as the Expanded Chronic Care Model (ECCM) [106] (Figure 1) integrates the CCM with the strategies and concepts from population health promotion for prevention of poor health.

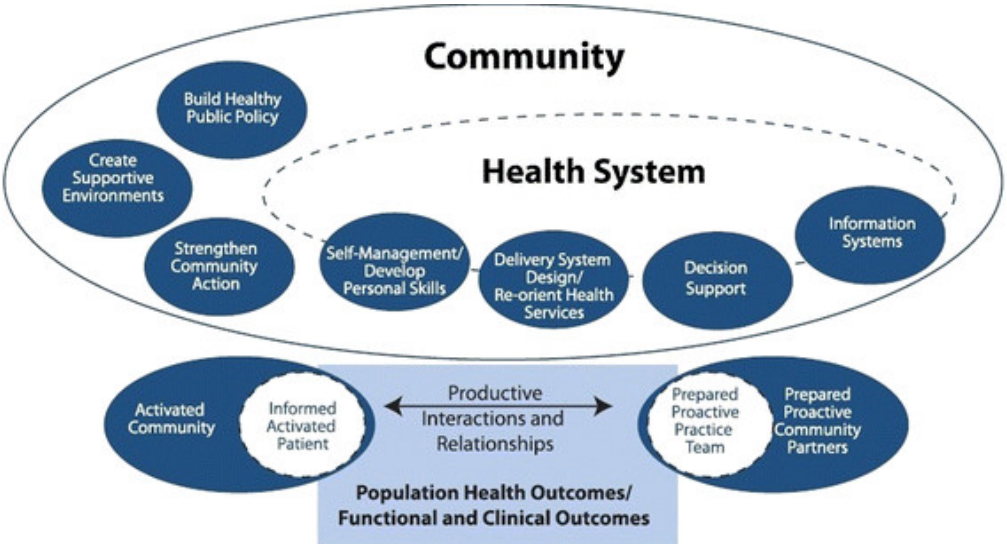

Figure 1. The Expanded chronic care model developed by Barr et al. [106].

In the graphical illustration of the ECCM (Figure 1) the porous border between the health system and community represent the flow of ideas, people and resources between these areas. As such, it extends self-management support outside the health services and expands the role of the community. The areas Self-management, Delivery System Design, Decision Support and Information System are kept from the original CCM [103] but they are now placed both in the health system and the community ovals. The areas Develop Personal Skills, Re-orient Health Systems, Build Healthy Public Policy, Create Supportive Environments and Strengthen Community Action are from the health promotion model Ottawa Charter [107]. By adding the areas from health promotion in the model the empowerment and engagement of communities to make healthy lifestyle choices becomes more apparent. In addition, an important part of the ECCM is to consider the health determinants with a focus on equity aspects [106].

ECCM is an action driven model that aims to broaden the focus of practice towards health outcomes on three different levels: individual, community and population. In this thesis self-management and prevention strategies located in the communities are central. Also, the setting of disadvantaged areas makes the equity aspect in particularly relevant. Therefore, the ECCM is suitable to use as a theoretical framework for this PhD project.

Self-management

Self-management support improves glycemic control [108] and self-management programs have shown to be effective in improving health behaviors (such as exercise habits), self-efficacy, and health status [87]. Both individually targeted interventions to improve self-management and metformin treatment have been shown to prevent or delay the onset of T2D [60]. When comparing the effectiveness of lifestyle intervention and metformin treatment, a significant difference in incidence of diabetes (58% versus 31%) was found between the groups [109]. Participation in lifestyle intervention programs also has important economic benefits [110, 111]. Lifestyle interventions for persons at high-risk are cost-effective and metformin only marginally cost-saving compared with placebo [111].

Information and motivation are often key strategies in promoting lifestyle modifications to improve self-management, although other reasons such as heavy burden of family obligations, may hinder patients from adherence, autonomy and access to social resources [112]. There is also a potential risk that promotion strategies blame individuals for poor health outcomes [22]. The empowerment approach is a patient centered approach that enables the patients to think critically and act autonomously, improve their self-efficacy and thereby take the lead in their self-management [113, 114]. This process has been suggested to fit particularly well for improving self-management of diabetes patients [113, 114].

Diabetes prevention efforts and diabetes management fall largely on the individual and are happening outside the formal healthcare setting. However, community engagement has demonstrated health benefits, particularly in disadvantaged population groups [77]. Thus, the importance of involving the community and networks within the community for diabetes prevention and management has been emphasized [1, 77].

The role of community

Physical location, shared perspectives, joint action or activities and social relationships are the main common domains describing the community [115]. Mac Queen et al. (2001) defines the community as a ”group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings” [115]. A sense of community belonging has been defined as knowing people well enough to ask them favors if needed, and for self-rated mental health the community belonging is associated with how many persons one knows in the neighborhood [116]. Community-centered practice means to work with rather than for communities, on goals set by the community itself

[117]. From this perspective the community can be viewed as the client to collaborate with and not simply the setting where the work is done. In this thesis the areas where the studies are situated are referred to as communities due to their geographical locations. These communities have in general shared low SES level. Despite the diversity in cultural and social background of persons living in these communities, the areas have been described by the residents as having shared beliefs, values and resources [118].

Social support

Social support is an important aspect of community engagement and critical for self-management [119-121], where peer mentoring or peer support can be an integral part of creating changes in programs to improve diabetes management [81]. Social support has also been found important for the disclosure of T2D, helping to adjust to a life with the T2D diagnosis and reduce negative diabetes-related emotions such as shame, that in turn has negative impact on self-management [122]. Family support in particular was found to be important for women across all socio-economic strata in making healthy dietary choices [82].

The perceived need of social support has shown to be more similar than different between native Swedes and foreign born persons with T2D, where the meaning of the concept of social support has been described mainly as information support on how to manage T2D [123]. The need for medical support and regular follow-ups was reported as more desired by the foreign born patients [123], while the need for emotional support was found more apparent among native Swedes [123], and more so among Swedish born women [124].

In a systematic review of 25 articles, there were studies showing that persons living with T2D benefit from peer support, although the evidence was too limited and inconsistent to conclude that peer support should be recommended for T2D patients [125]. Another systematic review reported gender differences in the effect of peer support [119]. Men wanted and received more often support from their spouses, while women wanted and received support from friends and other relatives [119]. Men were affected negatively when their spouses participated in weight loss education groups, while the opposite was found in women [119].

IMPLEMENTATION OF INTERVENTIONS IN 'REAL-LIFE' SETTINGS

Implementation trials are real-life tests of interventions and focuses both on the process of implementation, as well as the outcomes of the intervention [126]. The purpose is to understand *what, why* and *how* the intervention works in a real-life setting by testing approaches and improving them [127]. Mixed methods are recommended for implementation research [127] using process-, determinant- or evaluation frameworks [128]. To enable measurements and optimize the reproducibility, implementation strategies used in implementation trials should be named, defined and operationalized [129]. This is necessary to make the strategy comparable and evaluable. Proposed implementation outcomes are: acceptability, adoption, appropriateness, feasibility, implementation cost and sustainability [130].

Real-life studies analyse medical data collected under real life conditions and cope with "the noise" from a real life context [131]. RCTs have been seen as the "gold standard" providing evaluations on treatments efficacy, but this research design is not always suitable in real-life settings [132]. The internal validity of real-life studies are considered to be low, but they often have a high generalizability [132]. In implementation trials, the complexity increases at every level. Target populations become more heterogenous, interventions become more complex with multiple components and more actors are involved (patient, provider, team, service units, stakeholders, local organisations, community etc.). In implementation research, the users or actors of the research should optimally be involved in the implementation process [129].

Implementation studies often need to go through multiple stages of increasing complexity and scale, pointing towards the relevance of feasibility studies that focus on different aspects of the process. Feasibility studies are suitable to conduct when there is a need to decide if an intervention should be further tested for efficacy [133]. Feasibility studies aim to: 1) Evaluate the recruitment capability and resulting sample characteristics, 2) Refine and evaluate the data collection procedures and outcome measures, 3) Evaluate the acceptability and suitability of study procedures and the intervention, 4) Evaluate the resources and ability to manage and implement the study and the intervention, and 5) Evaluate the preliminary participant responses of the intervention [134]. Feasibility studies are formative, iterative and adaptive [135], with the purpose to build a foundation for a planned intervention in a larger scale [136]. Thus feasibility studies allow researchers assess if their ideas and findings can be formed to be relevant and sustainable [135].

SMART2D

SMART2D (Self-management approach and reciprocal learning for T2D) research project was a 5-year (2015-2019) multi-country diabetes project in Sweden, South Africa and Uganda [137]. The aim of the project was to strengthen the capacity for T2D care and evaluate the added benefit of a community component in improving self-management support. The project comprised formative, intervention development and trial phases. The intervention development was done in three steps: 1) Definition of intervention objectives and core strategies; 2) Designing generic intervention tools and training for core strategies and 3) Contextual translation of tools training and delivery [138]. SMART2D used the principle of standardizing by function rather than by content, hence the function of peer support was implemented differently in the three countries.

Our formative research work to develop a theory of change for the self-management process in all three settings shows that, in general, persons with T2D are aware of the self-management strategies needed for improved health but are unable to integrate these in their daily lives to the extent that would be required [139]. In all three countries a lack of perceived autonomy was found. This was expressed in relation to patient-provider consultations in Sweden and Uganda and as lack of dealing with T2D care and treatment in South Africa. Barriers were also reported related to the physical and sociocultural environment in all countries, suggesting a low self-efficacy [139]. The extent to which community actors were engaged in self-management support varied between the countries. In South Africa non-governmental organizations (NGOs) were actively engaged in self-management support, while in Uganda no relevant self-management support initiatives could be identified, although strong community initiatives existed for maternal and child health and HIV care. In Sweden NGO engagement was limited [118, 139]. In all three countries psychological support was received mostly from families and friends [139].

In Sweden specifically, a feasibility trial was conducted to assess the processes related to the implementation of a telephone facilitated health coaching intervention in socioeconomically disadvantaged areas. Participants were recruited through collaborating primary health care centers and community screening organized by SMART2D. A cluster randomized design was used to divide the participants into two groups; intervention: n=131; control: n=134. The Swedish SMART2D intervention consisted of nine telephone-facilitated health coaching sessions delivered individually by trained facilitators. The period of delivery was six months (November 2018 to May 2019). During the intervention participants received support through discussions on lifestyle related habits. The sessions were delivered mainly in Swedish or English by four trained facilitators, as well as in Spanish by one of the four facilitators and in Somali and Arabic by two additional skilled language facilitators. The facilitators followed a structured guide for each session. Excluding the introductory and concluding sessions, the remaining seven sessions focused alternately on healthy diet and physical activity (Table 2).

Table 2. Overview of session structure in the telephone-facilitated health coaching intervention

Session	Title	Content
1	Introductory session	Getting to know the program. Why work with a peer to make lifestyle changes?
2	Increase physical activity in daily life and reduce sedentary lifestyle	The importance of physical activity and how this can be increased in daily life
3	Healthy eating: Regular, balanced and healthy	The importance of regular, balanced and healthy meals
4	Physical activity through the life course	Discussion on how physical activity levels have changed over the years
5	Fruit and vegetables	The importance of eating fruit & vegetables every day
6	Increasing your daily physical activity	Discussion on current situation and potential possibilities for improvements
7	Sugar	How sugar consumption can be decreased in daily life
8	Finding a physical activity that suits you	Discussion of options/choices to physical activity
9	Healthy lifestyle - moving forward	How has it been to try to change to a healthier lifestyle and how can this be maintained?

In addition to the health coaching, participants were encouraged to identify, peers, friends and/or family members who could work with them and support them in their activities. The participants were also invited to attend inspiration meetings in their local community to meet each other, their facilitators and other SMART2D team members, representatives from primary care and collaborating citizens' service offices, as well as experts on diabetes, diet and physical activity.

3 RATIONALE

Disadvantaged population groups are affected by T2D to a higher extent. It is therefore critical to implement and evaluate support mechanisms for T2D prevention in socioeconomically disadvantaged areas where the diabetes burden is higher than in more affluent surroundings.

Detecting persons with asymptomatic T2D and at risk of developing the disease will enhance the possibilities to decrease suffering for many persons. Diabetes screening is one detection strategy used for this purpose. In this thesis the reach of two different diabetes screening approaches will be examined comparing community screening with facility-based screening. According to our knowledge no similar comparisons of screening reach have been conducted.

Implementation of interventions in real-life settings is not a straight forward process. To engage in lifestyle interventions the perceptions of diabetes risk are crucial. Therefore, it is relevant to increase the understanding of diabetes risk before designing and implementing a support intervention.

This thesis also investigates both the participant acceptability and interaction between facilitators and participants in a telephone-facilitated support intervention implemented in disadvantaged areas. The acceptability of interventions is central for adherence, and as such an important component to assess. The interaction between facilitator and participant influences the support process and it is therefore relevant to evaluate this aspect of the intervention. It is particularly important to improve knowledge on how support interventions work in these settings where the need of support is highest.

4 AIM AND RESEARCH QUESTIONS

Overarching aim:

To determine the feasibility of early detection and implementation of a self-management support intervention for T2D and persons at risk in socioeconomically disadvantaged areas in Stockholm.

Research questions for each of the sub-studies:

1. What are the perceptions of risk and the experiences of lifestyle modification among persons who have been at risk of developing diabetes over a ten-year period?
2. Who are reached through community- and facility-based screening when compared with demographic population data from the selected areas of Stockholm?
   What are the participant characteristics related to diabetes risk scoring between community- and facility-based screening?
3. What is the acceptability of the peer support format and content among the participants in socioeconomically disadvantaged areas in Stockholm?
4. How well does a developed scoring tool function to measure interaction between participants and facilitators in the support process?
   How does the interaction score vary between facilitators in the telephone-facilitated health coaching intervention?
   What are the enablers and challenges of the support, as described by the facilitators?

5 METHODS

OVERVIEW OF THE STUDIES AND RESEARCH METHODS

The table below summarizes the design and methods used in the four studies in relation to their main objectives (Table 3).

Table 3. Overview of data sources, design and methods

Study	Main objective	Data sources	Design and methods
I. Risk perceptions about prediabetes and experiences of lifestyle modification	To improve understanding of how older persons with a high risk of developing type 2 diabetes (T2D) manage and relate to the information about diabetes risk over a ten-year period of time	- 15 interviews with persons at risk of developing diabetes - Observations - Fieldnotes	Qualitative Qualitative content analysis
II. Reach of screening for early detection or high risk of T2D	To determine the difference in population-reach and participant characteristics between community- and facility-based screening for detection of high risk of diabetes or T2D	- Data from 2564 Finnish diabetes risk score (FINDRISC) forms (1827 community screening and 737 facility-based screening) - Population data from Statistics Sweden (Statistiska centralbyrån, SCB)	Quantitative Descriptive and limited inferential statistics
III. Acceptability of a prevention and self-management support intervention for T2D	1) To develop and assess the psychometric properties of a measurement scale for acceptance of telephone-facilitated health coaching intervention, based on the Theoretical Framework of Acceptability (TFA) 2) To determine the acceptability of the intervention among participants living with diabetes or having a high risk of developing diabetes in socioeconomically disadvantaged areas in Stockholm using the newly developed tool based on the TFA	- 49 Likert scale questionnaires on participant acceptability	Quantitative Exploratory factor analysis
IV. Interaction as part of the intervention delivery process of a prevention and self-management support intervention for T2D	To assess and explain the process of interaction between participants and facilitators in a telephone-facilitated health coaching intervention in terms of its dimensions, enablers and challenges	- 40 recorded telephone-facilitated health coaching sessions - 4 recorded and transcribed natural group discussions of quality assurance meeting with the intervention facilitators - Meeting notes	Mixed methods Quantitative: Exploratory factor analysis Qualitative: Thematic analysis

All studies within this research project are nested in the formative and trial phases of the SMART2D project. The scope of my work and how it fits within SMART2D are described in figure 2.

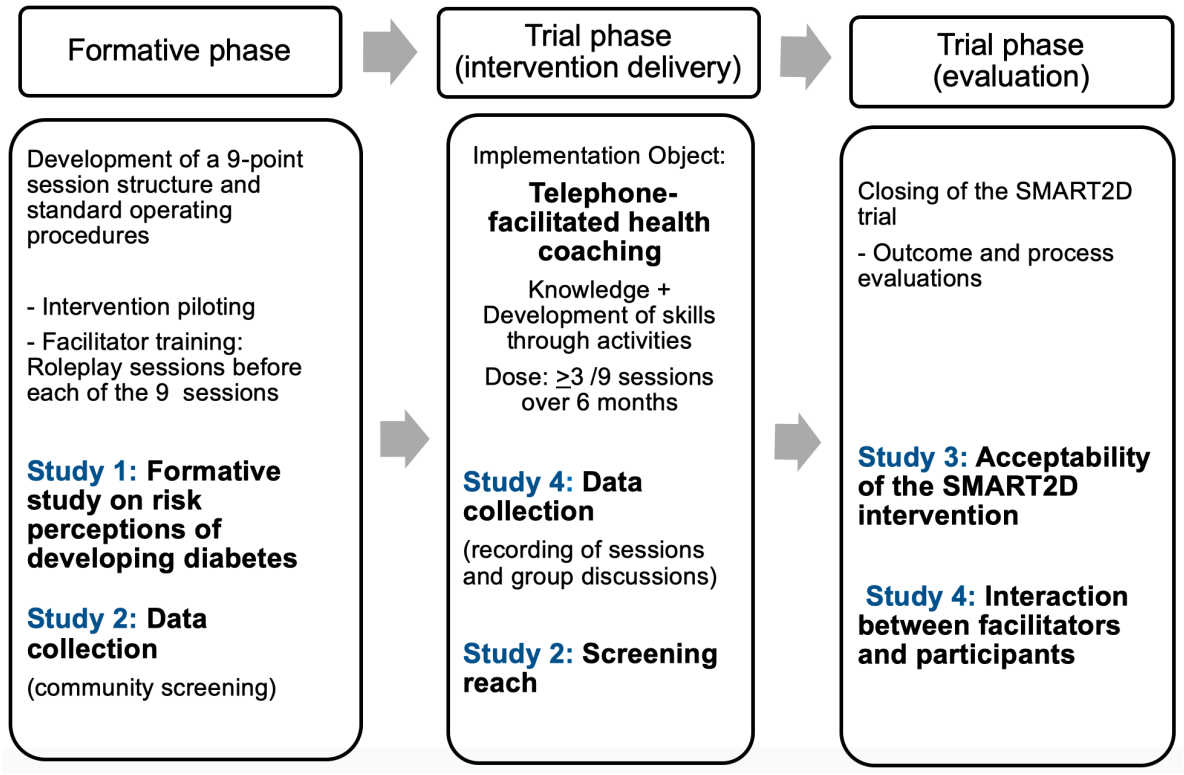

Figure 2. The four studies in relation to implementation of the Swedish SMART2D intervention

The four studies also relate to different parts of the Expanded chronic care model (ECCM) [106], marked in yellow in figure 3.

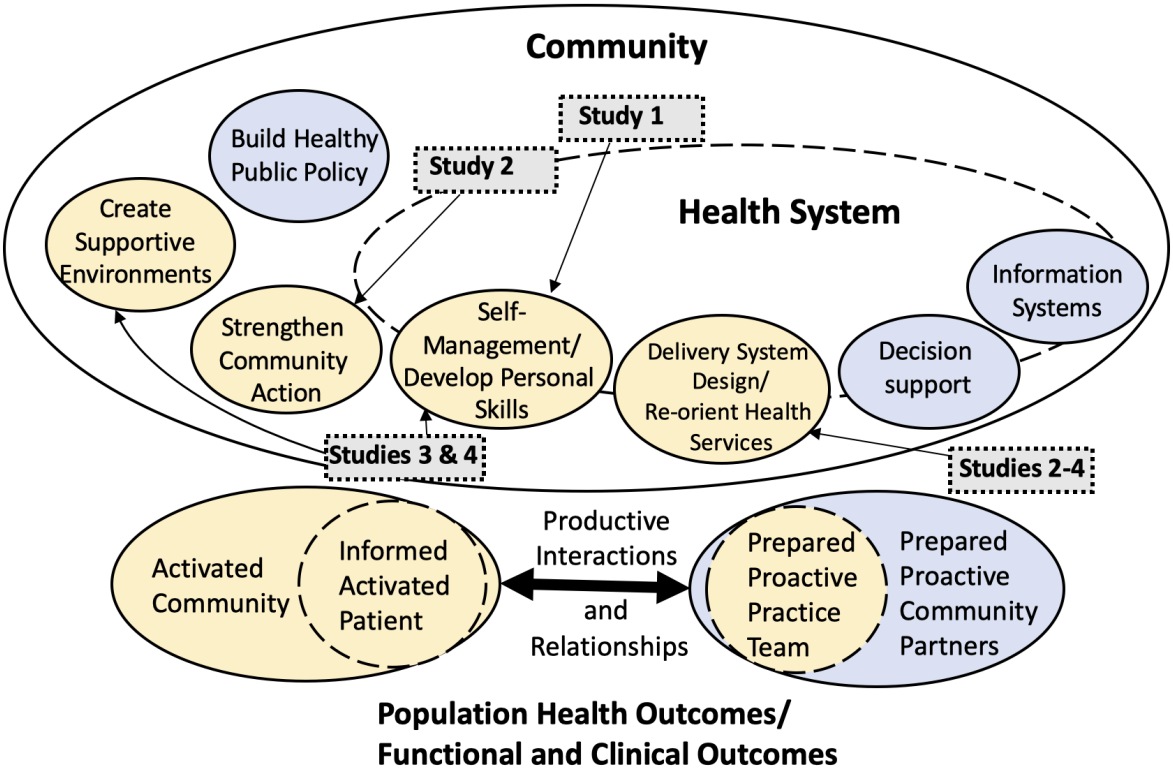

Figure 3. Conceptual framework showing how the four studies of this thesis relate to the Expanded Chronic Care Model [106]

Study 1, 3 and 4 are related to **Self-Management/ Develop Personal Skills**. Study 1 belongs to the community area and describes risk perceptions and experiences of lifestyle modification in terms of self-management outside the health system. Studies 3 and 4 are investigating different aspects (participant acceptability and interaction between facilitators and participants) of the SMART2D intervention, focusing on self-management support for persons with T2D and persons at risk of developing diabetes. Also, these two studies are placed in the community, since the support from the intervention is given outside the ordinary health system. The intervention component to encourage engagement in healthy activities together with a care companion, is part of **Create Supportive Environments** (study 3 and 4).

Study 2 belongs both in the community and the health system, as it is a comparison of the reach between community screening versus facility-based screening conducted in primary health care centres. The community screening required collaboration with local organisations and is therefore part of **Strengthen Community Action**. Studies 2-4 can also be seen as **Delivery System Design/ Re-orient Health Services.** In study 2 the focus is on the implementation of screening outside ordinary health services and in studies 3 and 4 the SMART2D supports individuals in the communities outside the traditional health care environment.

All studies (1- 4) aim to lead towards an **Activated Community** and have the potential to shape **Informed Activated Participants**, where in study 3 and 4 a **Prepared Proactive Practice Team** was active during the intervention.

SETTING

This research project is situated in socioeconomically disadvantaged suburbs of Stockholm. Persons living in these areas often have low income and educational levels and the unemployment rate is high. The areas also have a high proportion of immigrants compared to the overall Region Stockholm. T2D prevalence is higher in the non-European migrant populations in Sweden compared with native Swedes [140, 141], which explains the higher prevalence in socioeconomically disadvantaged suburbs with high numbers of immigrants [142]. Low educational levels are associated with higher prevalence of T2D in Sweden [143], as well as work stress and low sense of coherence [144]. In high income countries such as Sweden, the relative deprivation is more relevant to consider than the absolute poverty due to that the material conditions do not necessary reflect the health inequalities [145].

The areas where the main parts of the studies were conducted could be described as superdiverse neighbourhoods [146]. Superdiversity is a summary term not only taking into account a broader diversity in countries of origin, languages, and religions, but also acknowledging the differing statuses within groups of same ethnic or national origin [147]. Superdiverse areas are characterized by large numbers of migrants, where the increased migration have led to a wider range of ethnicities and spectra of countries, with the qualitative aspect of intra- and inter-group diversity such as socioeconomic status levels within ethnic groups and multiple immigration statuses [146, 147]. New migrants often move into already migrant dense areas with an impoverished elderly population [146]. A study on the Swedish population showed that in Sweden one-third of the burden of disease was unequally distributed and the disease burden was higher in socioeconomically disadvantaged population groups [148]. Overall, socioeconomically disadvantaged population groups experience poorer health and have lower life expectancy than their counterparts in more affluent groups [149], similarly with the ongoing COVID-19 (Coronavirus Disease 2019) pandemic.

The incidence rate of diabetes is falling in Sweden but the prevalence has increased by around 30% from 2005/2006 to 2012/2013 [150]. Previously (1991-2002) the incidence rates were increasing annually by 3%, but it levelled off around 2002 [151]. The incidence is predicted to decline further, although the prevalence is expected to increase in the coming years mainly due to demographic changes and improved survival of persons living with diabetes [151]. The overall prevalence of T2D in Sweden and Region Stockholm is around 5% [1, 151]. These figures, however, hide disproportionate prevalence rates across municipalities within the region [142].

In Sweden, primary health care (PHC) is most often the first point of contact when seeking care (preventive, curative and rehabilitation). According to the Swedish national guidelines for diabetes care and prevention, diabetes care is primarily provided at PHC level by a team of doctors and specialized nurses [152] comprising a diabetes care team. Patients with T2D have two scheduled medical visits at primary care per year [152], and persons with prediabetes have one visit per year [153]. Tests included for both sets of patients are HbA1c, blood pressure, and

anthropometric measurements such as weight and height. Additionally, blood cholesterol levels are measured annually for patients with T2D and every second year for patients with prediabetes [153]. Diabetes nurses provide lifestyle counselling as part of self-management support [152, 154]. Patients are referred to nutritionists, podiatrists, ophthalmologists and endocrinologists when there is a need for further care [154].

A study showed that non-Nordic immigrants were less likely to participate in diabetes programs in Sweden compared to the native Nordic population, but they were more likely to request more supportive care [155]. Fragmentation of the health care institutions has been identified as a problem within Swedish health care, owing to a lack of collaboration with and limited connection to community networks [118, 156].

PARTICIPANTS AND DATA COLLECTION

Study 1. Risk perceptions about prediabetes and experiences of lifestyle modification

To understand how persons perceived to live at risk of developing diabetes and hear about their experiences of potential lifestyle modifications, 15 qualitative semi-structured interviews were conducted. The participants in this study were enrolled in Stockholm Diabetes Prevention Program (SDPP) [157] 20 years earlier (1992-1998). They had received information about being at risk of diabetes around ten years earlier (2004-2005) than the interviews were conducted and had now lived with this knowledge for a decade. This gave us the unique opportunity to conduct interviews about their risk perceptions and experiences of living at risk of developing diabetes over a longer time period. In addition to the interviews, observations were conducted at a primary health care center (PHCC) where the participants were examined according to their diabetes risk status as part of their follow-up in SDPP.

The data were collected in 2016 and 2017 in two phases. At the time of data collection the participants had either a progression in their prediabetes status or they had reversed their glucose levels compared to their risk status in a SDPP follow-up ten years earlier. In the first phase, 5 interviews with participants with elevated glucose values and five with reversed values were included. After preliminary analysis, additional five interviews were conducted with participants who had reversed their diabetes risk. The sample size of data from 15 interviews had good information power and was considered appropriate [158]. The interviews were conducted in place of the participant's choice. Some of the participants preferred to be interviewed in their home environment while others wanted to meet in common places such as cafeterias or at the library in the participant's local community. After each interview analytical memos were compiled in a notebook to capture observations not recorded during the interviews.

Study 2. Reach of screening for early detection or high risk of T2D

This study investigated the reach of T2D screening and compared the characteristics of persons participating in community screening versus facility-based screening. The data used for this study was collected at the SMART2D community screening venues and facility-based screening conducted in PHCCs for Project 4D (Four Diagnoses) [159]. Both projects were connected to Karolinska Institutet and had used the Finnish diabetes risk score FINDRISC [52] as screening tool, with additional questions on the participants' demographic information.

The community screening was organized by SMART2D in 2017/2018 and the facility-based screening by the project 4D between 2014 and 2017 (data used for this study: 2014-2015). Although the screenings were conducted in different suburbs of Stockholm, the locations were similar in terms of being socioeconomically disadvantaged areas. The study included data from a total of 2,564 screened participants and this was compared with data on the eligible target population from the study areas from Statistics Sweden (Statistiska Centralbyrån, SCB) to assess reach.

Box 1. Diabetes screening by project 4D

4D project

- *Collaboration between Stockholm County Council and Karolinska Institutet*
- *Four diagnoses: Arthritis, Breast cancer, Type 2 diabetes and Heart failure*
- *Diabetes screening was conducted at primary health care centers in socioeconomically disadvantaged areas of Stockholm 2014 – 2017*
- *Recruitment in waiting rooms and by referral from health care providers*

https://ki.se/en/srp-diabetes/4d-type-2-diabetes-project

Study 3. Acceptability of a prevention and self-management support intervention for T2D

An acceptability tool was developed (for more information, please see description under subheading "Tools" in the analysis section) and tested to measure the participants' satisfaction of the Swedish SMART2D intervention. After the participants had completed the intervention, defined as participation in at least three of the nine telephone-facilitated health coaching sessions, the questionnaire was administered by a research assistant from the SMART2D team who had no prior contact with the participants. The survey was answered by 49 participants. The participants were either at high-risk of developing diabetes defined as having scored ≥13 on the FINDRISC test or being diagnosed with prediabetes or T2D.

Study 4. Interaction as part of the intervention delivery process of a prevention and self-management support intervention for T2D

A mixed methods study was designed to understand the dimensions of interaction between participants and facilitators in the SMART2D telephone-facilitated health coaching intervention. The quantitative part consisted of an assessment of interaction using a tool developed by the SMART2D team (for more information, please see the description under subheading "Tools" in the analysis section). Forty recorded health coaching sessions performed by four facilitators were scored independently by two observers.

The qualitative part consisted of data from four quality assurance meetings held with the four facilitators that delivered the majority of the health coaching sessions. The format of these meetings was natural group discussions [160] and they were held along with the intervention process. Two moderators attended the meetings and questions related to enablers and hinders in the intervention process were addressed and discussed. Meeting notes were taken during the sessions.

ANALYSIS

Qualitative data analysis

The fifteen interviews conducted in study 1 and the four natural group discussions [160] held with the facilitators in the qualitative part of study 4, were recorded and transcribed verbatim. Before starting the coding process, the recordings were listened to and the transcripts were read through several times to familiarize with the data. The notes from both interviews and group discussions were used as complement to confirm the transcribed material. The interview transcripts from study 1 were analyzed using conventional qualitative content analysis [161, 162], by searching for meaning units to define codes. The codes were further revised and categorized before a main theme was developed, in order to extend the analysis from a manifest to a latent level.

In study 4 a thematic analysis was carried out [163]. Three predefined themes were formed from the quantitative results and used deductively to find relevant meaning units from the data. In addition, other themes were developed inductively. The themes were organized by creating thematic maps. In this process some of the inductively developed themes became sub-themes to the predefined themes. The software program NVivo 10 was used in the coding process both for study 1 and 4. The analysis processes for both studies were triangulated within the research group to improve credibility as part of trustworthiness [164].

Quantitative data analysis

To compare the reach of community screening and facility-based screening in study 2, the data from the respective screenings and study sites was analyzed using STATA for descriptive and limited inferential statistics.

Exploratory factor analysis (EFA) is commonly used in tool development allowing for refining, and evaluating tests and scales. It is used to reduce large sample sizes and uncover the underlying relationships between measured variables. Despite the limited sample sizes in studies 3 and 4 (study 3: n=49 and study 4 n=40) it was possible to conduct EFA [165].

The appropriateness of data for EFA was tested by performing the Bartlett's test of sphericity, Kaiser-Meyer-Olkin (KMO) test. Criterion validity was determined through Spearman's rank correlation coefficients. Items with maximum loadings less than 0.40 were dropped. The internal consistency of the tool was assessed using Cronbach's alpha, where scores between 0.7 and 0.9 were deemed appropriate [166]. Likert summated scales were calculated for each participant within the identified construct from the EFA. The sum-scores were standardized by multiplying the sum-score by $100/m \times k - 1$ [167]. A Wilcoxon rank-sum test was conducted to detect differences.

Tools

Three different tools were used in the quantitative parts of this research project.

Study 2 used data from the validated risk assessments tool FINDRISC, consisting of eight questions about risk factors of diabetes (age, body mass index (BMI), waist circumference, level of physical activity, consumption of vegetables, fruits and berries, history of antihypertensive drug treatment, history of high blood glucose values and family history of diabetes) [53, 168] used to detect asymptomatic T2D identify individuals at high risk of developing T2D. In the original FINDRISC questionnaire a total of 26 points can be achieved. However, in the modified version used by both SMART2D and 4D project in this study, the maximum score was 25 points, having a maximal score of two instead of three for the question on BMI. In addition to the original FINDRISC questions, questions were added on information about the participant's and her or his parents' place of birth. These additional questions were not included in the risk scoring.

The tool developed for study 3 was based on Sekhon's Theoretical Framework of Acceptability (TFA) using the seven suggested domains: affective attitude, burden, perceived effectiveness, intervention coherence, opportunity costs, self-efficacy and ethicality [140]. A 5-point Likert scale ranging from strongly agree to strongly disagree was used to capture participant responses. Questions included in the acceptability tool are shown in figure 4.

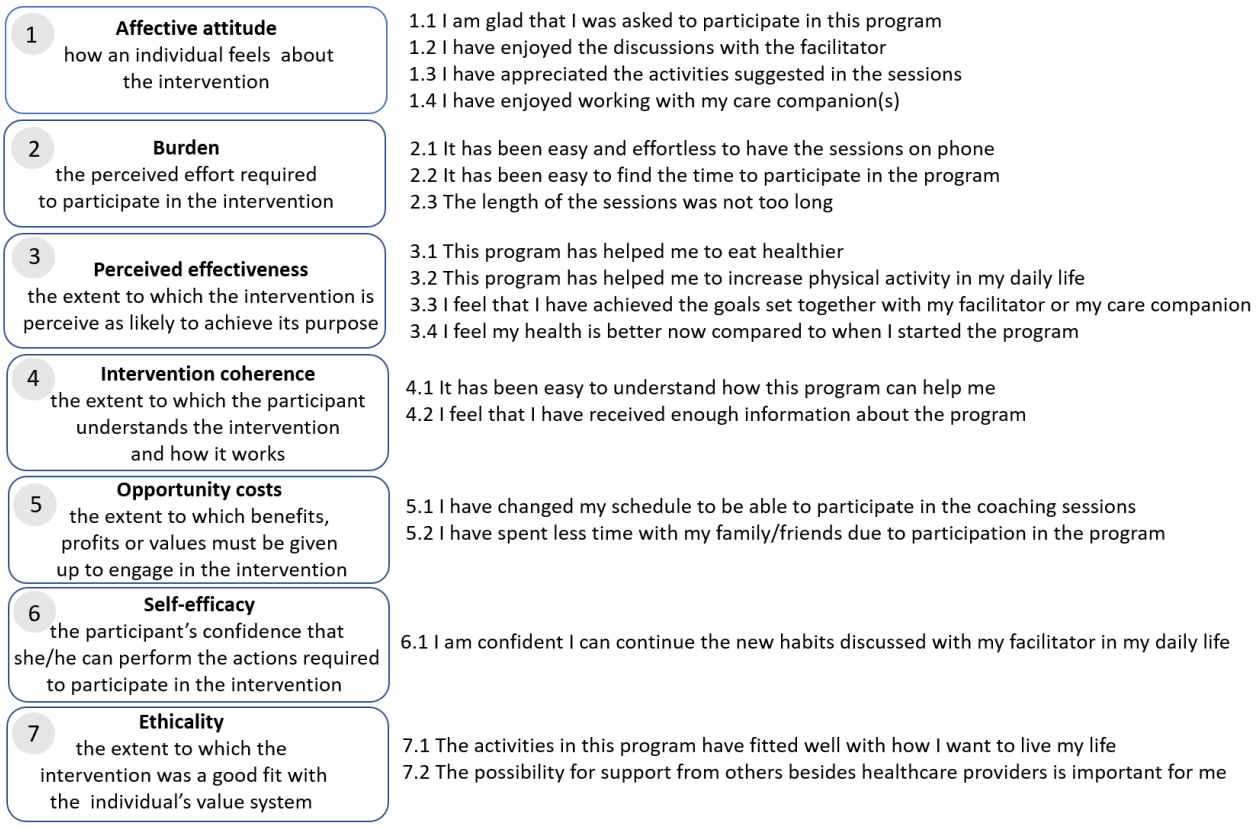

Figure 4. The questions developed by SMART2D related to the seven domains from Sekhon's Theoretical Framework on Acceptability

In study 4 we developed an interaction scoring tool based on four different dimensions of interaction. The tool had a 5-point Likert scale format and consisted of a total of 23 statements. The questionnaire covered the following interaction aspects: 1) Utilization of Strength-based behavioral coaching strategies by the facilitator, 2) Creation of collaborative relationship, 3) Delivery of intervention content, and 4) Participant engagement, measured by how large part of the session (estimated in percentage) the facilitator was talking. Figure 5 shows the statements included in the scoring tool.

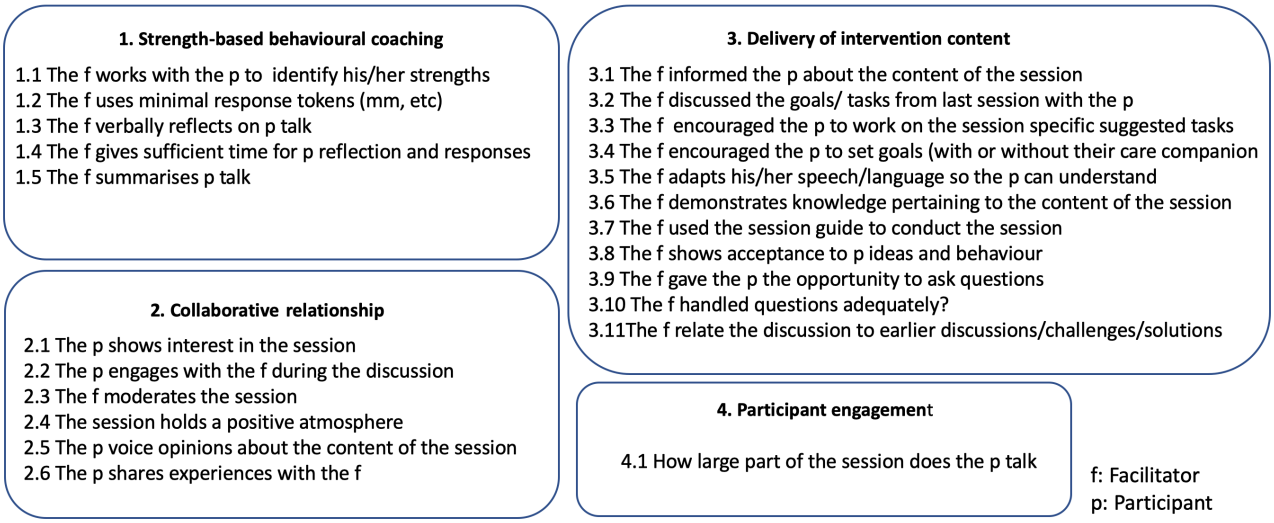

Figure 5. Statements included in the interaction scoring tool in relation to different dimensions of interaction

Reflexivity and my roles

It is recognized that awareness and openness about the researcher's own influence in all stages in the research process, i.e., reflexivity, is essential for transparency [169]. My background as an occupational therapist and focus on meaningful activities was useful in the development of the structured guide and material used for the Swedish SMART2D intervention. The interviews conducted for study 1 could potentially have been influenced due the activity perspective I have from my profession as an occupational therapist in terms of prompting during the discussions.

My role as an implementation manager for SMART2D implied close contact with various stakeholders as a major part of the implementation work. The shift of my role as the implementation manager for SMART2D to become a full time PhD student was a bit difficult to manage initially, since I was very involved in different parts of SMART2D work not directly related to my own studies. At the same time all parts of working with SMART2D have influenced this PhD project. To have the position as an implementation manager was an advantage to get the full picture of the processes in implementing a complex intervention and it enabled me to be completely involved.

In both study 3 and 4, I was actively involved through all phases of the quantitative parts, from tool development to final analysis. In study 4, I was one of the two persons scoring and analyzing the 40 sessions included in the study. To listen to the coaching sessions conducted by my colleagues from the SMART2D team, required awareness of staying strict to the scoring tool and not be influenced by familiar voices when assessing the interaction in the sessions. In the qualitative data collection for study 4, I was also one of the meeting moderators and the note taker. Both mentors and the facilitators were team members of the SMART2D project,

which could have led to social desirability bias [170]. Although the established relationship between all team members could have been positive in the sense of building rapport [160].

Overall, study 3 and 4 evaluating different aspects of the SMART2D intervention have required an awareness of separating my feelings of being highly involved in the different phases of development and implementation of the intervention, which could have made me less neutral to the project. I therefore had to actively look beyond this and try to stay as objective as possible in the analysis and the interpretations of findings. On the other hand, the experiences I have from the time of being the implementation manager for SMART2D have been a great advantage in my understanding of the study context, which has helped me a lot in developing my research.

ETHICAL CONSIDERATIONS

The SMART2D intervention promotes the social component of healthy lifestyle activities both in collaboration with a care companion but also via general meetings arranged for participants to meet each other. From this aspect, participation in SMART2D has the potential benefit of strengthening the social networks for diabetes prevention and management. The potential benefit of the participation in the diabetes screening would be if diabetes/prediabetes is detected and they receive earlier care than without the screening. On the other hand, a potential risk of screening could be that participants receive information about being at risk and that the risk information causes worry and anxiety.

To be able to make choices in terms of lifestyle modification, it is highly important that participants are given sufficient information to make their own decisions. Before conducting each interview (study 1), the participant was asked to read through an information letter and give both written and oral informed consent. Informed consents were not taken to conduct the SMART2D community screening (study 2) unless the participants were enrolled in the SMART2D trial. No names or other personal details were recorded when conducting the FINDRISC assessment, comparable to FINDRISC tests that are available online. All participants who took part in the facility-based screening (study 2) signed consent forms before the FINDRISC questionnaire was administered as it was taken as part of other measurements and recorded in patient registers.

Persons screened at the community screening venues arranged were referred to the collaborating PHCs at the study sites for further testing when they scored ≥13 on the FINDRISC test alternatively had HbA1c values ≥42. This was possible only if they were registered or wanted to be registered at these PHCCs. In cases when screening participants

preferred to visit another PHCC, they were recommended to tell their health care providers about their diabetes risk status assessed at the SMART2D screening. Participants received the test results from the FINDRISC scoring and HbA1c test, together with information leaflets containing self-management advice. The phone number to SMART2D was on the leaflets, allowing participants or health care providers to call for clarification or more information as needed.

Enrollment in the SMART2D project was done at collaborating health care centers or at the community screening venues. Participants were given information verbally and the consent form included information to read before signing. The information letter included a project description with the aim of the research project, potential benefits and risks, right to withdraw at any time etc. The participants were divided into intervention and control groups and provided the corresponding version of the consent form. ID-numbers were used to anonymize the participants when sharing information within the project. In accordance with the General Data Protection Regulation (GDPR), the data management program Research electronic data capture (REDCap) [171] was used to store data collected from the participants and the notes from the health coaching sessions. Only researchers/SMART2D team members had access to the REDCap system. Facilitators asked the intervention participant for permission before starting coaching sessions. To record and analyze the quality assurance meetings, facilitators from the SMART2D team approved the process (study 4).

Enrollment of participants to lifestyle interventions because of risk of developing diabetes can be sensitive since there is a risk that a participant can feel blamed about having a non-healthy lifestyle that needs to be changed. Also, unhealthy behaviors are strongly associated with social position and thereof not individual choices to the same extent as caused by structural factors. Moreover, T2D and diabetes risk are often associated with overweight and obesity and the risk of stigma should be considered. In terms of the principle of autonomy, a question to be raised is whether the intervention interferes with the participant's free will although from the perspective of virtue ethics, the intention is to "do good". If the participants manage to change their lifestyles in terms of increased physical activity and healthier dietary habits because of participation in the intervention, this can improve their health outcomes.

Study 1 was approved by the Stockholm Ethical Review Board (ID: 2016-353- 32). Studies 2-4 have ethical approvals through SMART2D approved by the Stockholm Ethical Review Board (ID: 2016/2521/31/1). Study 2 has an additional approval for the data used from 4D, approved by the Stockholm Ethical Review Board (ID: 2013/2303-31).

6 RESULTS

OVERVIEW OF MAIN FINDINGS

In the table below the main findings answering the respective research questions is presented (Table 4).

Table 4. Overview of the main findings

Study	Research questions	Main findings
I. Risk perceptions about prediabetes and experiences of lifestyle modification	What are the perceptions of risk and the experiences of lifestyle modification among persons who have been at risk of developing diabetes over a ten-year period?	○ Diabetes risk is not urgent to act upon ○ External triggers, such as diagnosis (T2D or other) are needed for behavior change ○ Partner's diagnosis is a reason for dietary changes
II. Reach of screening for early detection or high risk of T2D	1) Who is reached through community- and facility-based screening when compared with demographic population data from the study areas? 2) What are the participant characteristics related to diabetes risk scoring between community- and facility-based screening?	○ Community screening reaches non-European (African and Asian) born persons to a higher extent compared with facility-based screening, while European born persons are reached more through health facilities ○ Younger persons are screened in the community compared to the facility ○ More women than men are reached through both screening approaches
III. Acceptability of a prevention and self-management support intervention for T2D	What is the acceptability of the peer support format and content among the participants in socioeconomically disadvantaged areas in Stockholm?	○ Acceptability of the SMART2D intervention was high in terms of 'affective attitude' and 'coherence and understanding' ○ The intervention was perceived more burdensome for younger participants and persons at risk of developing T2D
IV. Interaction as part of the intervention delivery process of a prevention and self-management support intervention for T2D	1) How well does a developed scoring tool function to measure interaction between participants and facilitators in the support process? 2) How does the interaction score vary between facilitators in the telephone-facilitated health coaching intervention? 3) What are the enablers and challenges of the support process, as described by the facilitators?	○ 'Collaborative relationship', 'Delivery of the intervention content' and 'Strength-based behavior coaching' were the three interaction dimensions revealed from Exploratory factor analysis ○ Differences in the intervention delivery were found between the facilitators both from the quantitative and qualitative analysis ○ Goalsetting was found challenging and the facilitators used different approaches ○ Limited language skills were perceived a hinder in the intervention delivery

STUDY 1: RISK PERCEPTIONS ABOUT PREDIABETES AND EXPERIENCES OF LIFESTYLE MODIFICATION

When understanding of risk perceptions and the experiences of lifestyle modification among persons at risk of developing diabetes is analyzed over time, it was found that diabetes risk was not threatening enough for changing lifestyle.

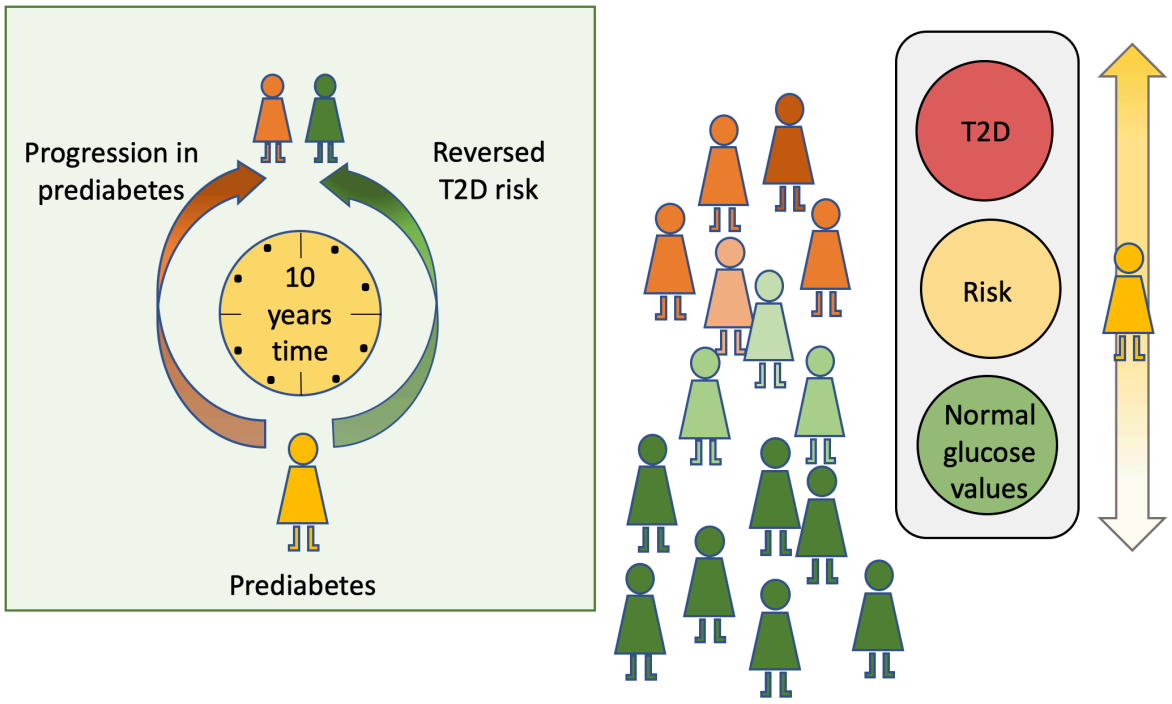

Figure 6. Graphical abstract of study 1

The findings were organized in three categories: 1) T2D risk is not urgent enough to change behavior, 2) Adaptations in everyday life as a part of aging, and 3) Diagnosis as motive for change. From these categories the main theme 'T2D risk is not concrete enough to motivate lifestyle modification without other external triggers' was formed (Table 5).

Table 5. Main theme developed from three categories

Theme	Category	Sub-category
T2D risk is not concrete enough to motivate lifestyle modification without other external triggers	T2D risk is not urgent enough to change behavior	○ Difficult to understand what T2D risk means ○ Information is not enough for change
	Adaptations in everyday life as a part of aging	○ Common habits change together with others ○ Lifestyle modification trade offs
	Diagnosis as motive for change	○ T2D diagnosis as reason to change habits ○ Other diagnosis than T2D as motive for change

The results revealed that being at risk of developing T2D alone is not enough for making lifestyle modification. While T2D was seen more as concrete and structured, a high-risk status was not considered as concrete enough to be taken seriously. Instead it was seen as something diffuse and fictive, especially if there were no signs and symptoms:

I think I would worry if I felt symptoms, this with bad blood circulation and sensations in the feet… Impaired vision. Or something like that, but I don't have these warning signs. (ID: 6)

External triggers such as diagnosis of T2D as well as other diagnoses were reported as reasons to modify lifestyle. Also, a partner's diagnosis motivated changes, in particularly changes in dietary patterns. The risk of developing diabetes was not perceived as threatening enough to justify lifestyle modifications. In the group of participants who had reversed their diabetes risk to normal glucose values, more than half of them reported other diagnoses (own or in a partner) as reasons for the change in habits. ID: 2,10 and 13 had reversed the risk after receiving other diagnosis than T2D and ID: 1, 7 and 11 could have reversed their risk because of their partners' diagnosis that indirectly led to changes in their diets (Table 6).

Table 6. Perceptions of risk and lifestyle modification over time

Participant ID	Recruitment status	Perception of risk at the first follow up 2004 – 2005	Lifestyle modifications between first and second follow up	Perception of risk at the second follow up 2014 – 2017
1	Reversed T2D risk	Yes, at risk	Active lifestyle changes because of T2D risk and weight reduction	Reversed T2D risk
2	Reversed T2D risk	Yes, at risk	Dietary changes because of stomach problems	Reversed T2D risk
3	Reversed T2D risk	No, not at risk *"It was ok"*	No active lifestyle changes	Don't know
4	Progression of T2D risk	No, not at risk *"I interpreted it as it was good"*	No active lifestyle changes	Increased T2D risk
5	Progression of T2D risk	No, not at risk *"No, I haven't received a response"*	No active lifestyle changes because of T2D risk. Eats healthy and is physically active	No change
6	Progression of T2D risk	Yes, at risk	No active lifestyle changes	Increased T2D risk, but *"Nothing alarming"*
7	Reversed T2D risk	Yes, at risk	Active lifestyle changes because of T2D risk	Reversed T2D risk
8	Progression of T2D risk	Yes, at risk	No active lifestyle changes 10 years back, but active lifestyle changes after information from the last follow up	Increased T2D risk (interpreted as diabetic values)
9	Progression of T2D risk	Yes, at risk	No active lifestyle changes	Increased T2D risk
10	Reversed T2D risk	Yes, at risk	Dietary changes because of stomach problems	No change
11	Reversed T2D risk	No, not at risk *"Not at a particular risk"*	Dietary changes because partner's change in choices of food	No change
12	Reversed T2D risk	No, not at risk	No active lifestyle changes	Reversed T2D risk
13	Reversed T2D risk	Yes, at risk	Dietary changes because of stomach problems	Reversed T2D risk
14	Reversed T2D risk	No, not at risk *"But maybe I have always had a little risk"*	Dietary changes to reduce weight	Increased T2D risk
15	Reversed T2D risk	Yes, at risk	Active lifestyle changes because of T2D risk	Reversed T2D risk

Table 6 is published in the article: Timm L, Daivadanam M, Lager A, Forsberg B, Östenson CG, Mölsted Alvesson H. "I Did Not Believe You Could Get Better"- Reversal of Diabetes Risk Through Dietary Changes in Older Persons with Prediabetes in Region Stockholm. Nutrients. 2019.

Many participants compared the T2D diagnosis with cancer, without any prompting, and it was perceived as much more frightening than T2D risk:

For me, it [the risk of diabetes] is not so bad. The fear is when they say that you have a tumor, malignant. (ID: 2)

Although exceptions were found, such as a few participants who took action because of the change in risk status, most did not make any lifestyle changes due to risk status alone. Also, T2D was not seen as a hindrance to continuing life as usual, with only minor adjustments:

No, because I know that if I develop diabetes, it is possible to live a good life anyway. And at the same time when you come to that situation, perhaps you can think of keeping sugar values down more. To walk or move and then kind of eat up your own sugar, or not consume wrong foods. (ID: 9)

All the participants appreciated receiving information about their risk status, as it was seen as an opportunity to prevent T2D. Despite this the majority did not make lifestyle changes after being informed about an increased diabetes risk. There was also a confusion over the concept of reversibility and about what the numbers from test results could mean:

I was a little unsure of what I was told ... I interpreted the answer of elevated values as it could mean normal, because it wasn't a diagnosis. And it made me unsure about the answer. So, I did not dare to interpret it as anything else than that I remained at risk as before, because I didn't believe you could get better. That you remain where you are. So that's my interpretation. (ID: 10)

In line with the quote above, many participants had interpreted their risk status differently to what was intended by their healthcare providers (Table 6).

The results from this study were combined with other formative studies to develop the SMART2D intervention.

STUDY 2: REACH OF SCREENING FOR EARLY DETECTION OR HIGH RISK OF T2D

This study compared the reach of community screening with facility-based screening. The data from the screened population were further compared with population data from the four socioeconomically disadvantaged areas where the study was conducted.

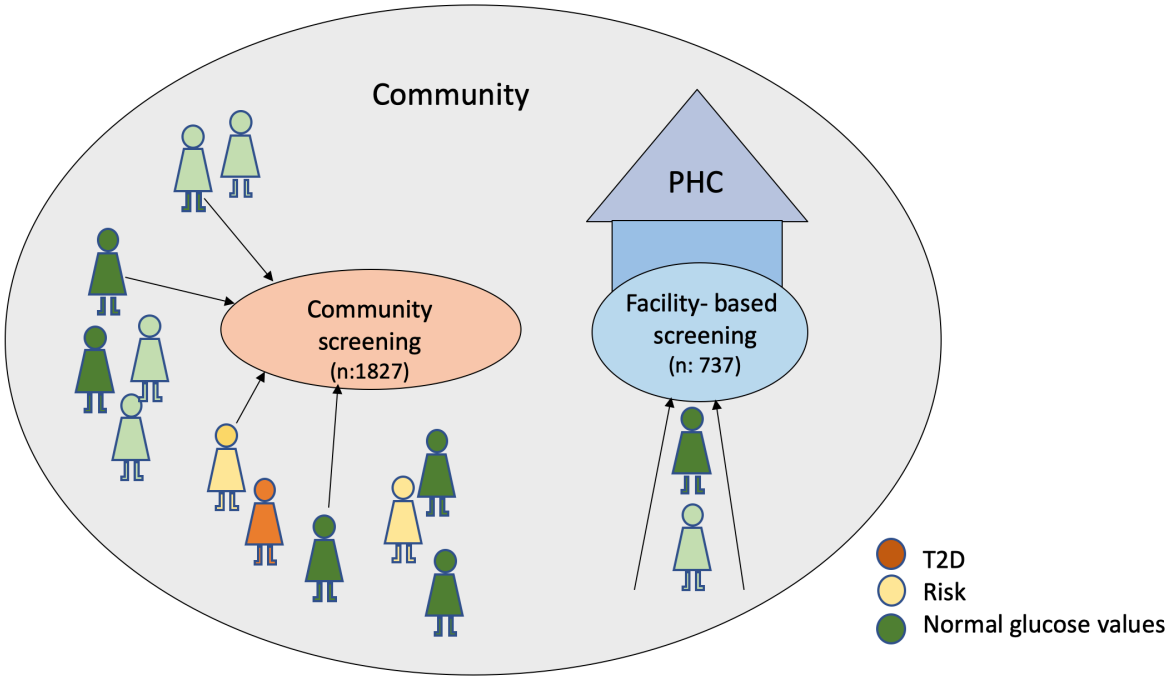

Figure 7. Graphical abstract of study 2

The main findings were that persons born in non-European countries (continents of Africa and Asia) were reached to a significantly higher extent through community screening compared with facility-based screening ($p < 0.001$), while people born in Sweden and other European countries were reached more frequently by facility-based screening. Significantly less European born persons were reached at the community screenings compared with the population from the study areas. An overview of the screening reach is given in table 7.

Table 7. Comparison of proportions and representativeness for the two screening methods with respect to the eligible population

Study site	**Community screening compared with Facility-based screening**			**Community screening compared with eligible target population from the study areas**			**Facility-based screening compared with eligible target population from the study areas**		
	Community (%)	Facility (%)	P-value	Community (%)	SCB Com. (%)	P-value	Facility (%)	SCB Fac. (%)	P-value
Age groups									
Total (n)	1822	737	Chi2	1822	41979	Pr-test	737	31368	Pr-test
18-24	91 (5)	19 (3)	0.007	91 (5)	5315 (13)	< 0.001	19 (3)	4034 (13)	< 0.001
25-64	1461 (80)	522 (71)	< 0.001	1461 (80)	29539 (70)	< 0.001	522 (71)	21467 (68)	0.099
65-79	235 (13)	196 (27)	< 0.001	235 (13)	5575 (13)	0.861	196 (27)	4460 (14)	< 0.001
80-89	35 (2)	0 (0)		35 (2)	1550 (4)	< 0.001	0 (0)	1407 (4)	< 0.001
Sex									
Total (n)	1827	737		1827	56363		737	40319	
Female	1030 (56)	416 (56)	0.975	1030 (56)	27852 (49)	< 0.001	416 (56)	20059 (50)	< 0.001
Male	797 (44)	321 (44)	0.975	797 (44)	28511 (51)	< 0.001	321 (44)	20260 (50)	< 0.001
Place of birth									
Total (n)	1827	737		1827	56363		737	40319	
Africa	564 (31)	22 (3)	< 0.001	564 (31)	6126 (11)	< 0.001	22 (3)	2218 (6)	< 0.001
Asia	706 (39)	183 (25)	< 0.001	706 (39)	9031 (16)	< 0.001	183 (25)	7405 (18)	< 0.001
North & Central America	6 (0)	5 (1)	0.220	6 (0)	308 (1)	< 0.001	5 (1)	218 (1)	< 0.001
South America	56 (3)	46 (6)	< 0.001	56 (3)	1009 (2)	< 0.001	46 (6)	1067 (3)	< 0.001
Europe	132 (7)	76 (10)	0.010	132 (7)	6844 (12)	< 0.001	76 (10)	5962 (15)	< 0.001
Only Sweden	363 (20)	405 (55)	< 0.001	363 (20)	32934 (58)	< 0.001	405 (55)	23359 (58)	0.093
Unknown					91 (0)			90 (0)	

SCB Com: Population eligible for screening from the community screening sites
SCB Fac.: Population eligible for screening from the facility-based screening sites
SCB: Statistics Sweden

The community-based screening also reached significantly more people at younger ages (age group 25-64 years), while the facility-based screening reached older persons (age group 65-79 years). The gender distribution was equal between the two screening groups, although both types of screening reached a larger proportion of women. This was also apparent when comparing the population data from the study areas (Table 7). The participants screened at health facilities were more overweight, reported having taken medication for high blood pressure and more commonly had high glucose values at some point as compared to earlier in life. Also, a family history of diabetes was reported to a higher degree among this group. Reported physical activity did not differ between the groups. The median FINDRISC score was 10 for participants in the community screening and 12 among participants screened at the facilities. An overview of the comparison between community and facility-based screening is given in table 8.

Table 8. Comparison between community screening and facility- based screening using the variables from the Finnish diabetes risk score (FINDRISC)

Variables	Total (N=2564)	Community (n= 1827)	Facility (n=737)	P-value [a]
Age median (IQR)	50 (38-61)	48 (37-59)	56 (43-65)	< 0.001
	n (%)	n (%)	n (%)	
Sex				
Female	1446 (56)	1030 (56)	416 (56)	
Male	1118 (44)	797 (44)	321 (44)	0.975
BMI				
≤25	890 (35)	692 (38)	198 (27)	
>25	1674 (65)	1135 (62)	539 (73)	< 0.001
Waist				
Women				
≤88	480 (33)	370 (36)	110 (26)	
>88	966 (67)	660 (64)	306 (74)	0.001
Men				
≤102	701 (63)	556 (70)	145 (45)	
>102	417 (37)	241 (30)	176 (55)	< 0.001
Physical activity 30 min/day				
Yes	1787 (70)	1271 (70)	516 (70)	
No	777 (30)	556 (30)	221 (30)	0.824
Intake of vegetables or fruit every day				
Yes	1671 (65)	1221 (67)	450 (61)	
No	893 (35)	606 (33)	287 (39)	0.005
Medication for high blood pressure				
Yes	606 (24)	383 (21)	223 (30)	
No	1958 (76)	1444 (79)	514 (70)	< 0.001
Elevated glucose values earlier in life				
Yes	485 (19)	315 (17)	170 (23)	
No	2079 (81)	1512 (83)	567 (77)	0.001
Family history of diabetes				
Yes	1412 (55)	964 (53)	448 (61)	
No	1152 (45)	863 (47)	289 (39)	< 0.001
Born in Europe				
Yes	989 (39)	503 (28)	486 (66)	
No	1575 (61)	1324 (72)	251 (34)	< 0.001
FINDRISC score				
<12	1348 (53)	1048 (57)	300 (41)	
≥12	1216 (47)	779 (43)	437 (59)	< 0.001
FINDRISC score median (IQR)	11 (8 – 14)	10 (7 – 14)	12 (9 – 16)	< 0.001[b]

[a] = P-value is calculated using Chi-squared tests for proportions, except those marked [b]
[b] = P-value is calculated using Wilcoxon rank sum test of equality of medians

Table 7 and table 8 are published in the article: Timm L, Harcke K, Karlsson I, Sidney Annerstedt K, Alvesson HM, Stattin NS, Forsberg BC, Östenson CG, Daivadanam M. Early detection of type 2 diabetes in socioeconomically disadvantaged areas in Stockholm–comparing reach of community and facility-based screening. Global Health Action. 2020.

STUDY 3: ACCEPTABILITY OF A PREVENTION AND SELF-MANAGEMENT SUPPORT INTERVENTION FOR T2D

The third study explored the acceptability of the Swedish SMART2D intervention from the participants' perspectives.

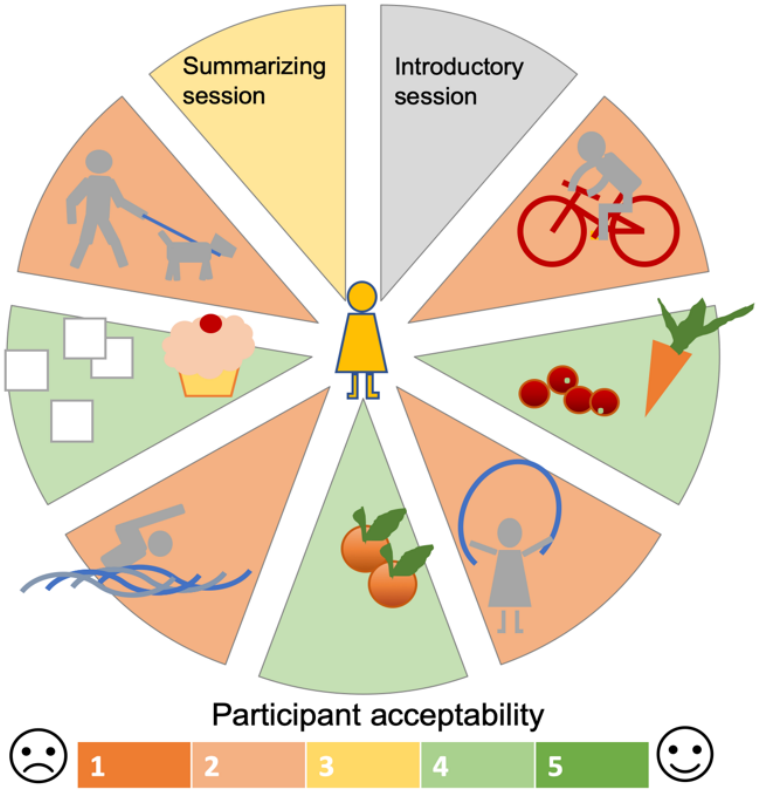

Figure 8. Graphical abstract of study 3

The majority (62%) of respondents were at high risk of developing diabetes. The age of the high- risk participants was in general lower than the age of participants with T2D. Overall the SMART2D trial had more female participants, which was apparent in this study as well. The majority (67%) of participants were born outside Sweden. The participants in the acceptability trial and those excluded from it differed significantly only in terms of the number of intervention contacts (Table 9).

Table 9. Participant characteristics

	Diabetes n (%) n=19	High-risk/ prediabetes of diabetes n=30	Total from the Acceptability study n=49	Excluded from the Acceptability study n=23	p-values
	19 (38)	30 (62)			
Sex					
Female	10 (53)	25 (83)	35 (71)	14 (61)	0.370^
Male	9 (47)	5 (17)	14 (29)	9 (39)	
Age*	58 (48-65)	44 (38-57)	49 (40-60)	53 (46-64)	0.129†
Younger	46 (40-49)	39 (36-43)	41(36-44)	45 (41-46)	0.231†
Older	64 (58-69)	59 (57-69)	60 (57-69)	60 (53-66)	0.834†
Number of intervention contacts					
3 or more	19 (100)	28 (93)	47 (96)	2 (9)	0.000^
Less than 3	0 (0)	2 (7)	2 (4)	21 (91)	
Median (IQR)	9 (4-10)	8 (4-10)	8 (4-10)	1 (0-1)	0.000†
Place of birth					
Sweden	10 (53)	6 (20)	16 (33)	5 (21)	0.342^
Outside Sweden	9 (47)	24 (80)	33 (67)	18 (79)	

*median, ^ Chi-square test, † Kruskal-Wallis test, IQR: Interquartile range
p-values compare the difference between the acceptability and excluded study sample.

A tool was developed based on Sekhon's Theoretical Framework of Acceptability (TFA) [172], with a 5-point Likert scale format containing 19 statements related to participant satisfaction. EFA was conducted to assess the validity of the acceptability domains from the TFA. After excluding two items with maximum factor loadings less than 0.40, 17 of 19 statements revealed three constructs: *Affective attitude and effectiveness* (how the participants felt about the intervention and the extent to which the intervention was perceived as likely to achieve its purpose) and *Coherence and understanding* (describing the extent to which the participants understood the intervention, how it addressed their condition and how it worked) and *Perceived burden* (perceived amount of effort that was required to participate in the intervention). The three constructs accounted for 51%, 17% and 14% of the variance respectively, giving a total of 82%. Cronbach's alpha for the respective constructs were 0.90, 0.77 and 0.85, indicating an appropriate level of internal consistency for each construct [173] (Table 10).

Table 10. Factor loadings from exploratory factor analysis and respective Cronbach's alpha scores for the final domains

	Affective attitude and effectiveness	Coherence and understanding	Perceived burden
This program has helped me to eat healthier	0,91		
The possibility for support from others besides healthcare providers is important for me	0,88		
I have enjoyed the discussions with the facilitator	0,87		
This program has helped me to increase physical activity in my daily life	0,68		
It has been easy to understand how this program can help me	0,68		
I have appreciated the activities suggested in the sessions	0,66		
I feel my health is better now compared to when I started the program	0,65		
The activities in this program have fitted well with how I want to live my life	0,55		
I am confident I can continue the new habits discussed with my facilitator in my daily life	0,49		
I am glad that I was asked to participate in this program	0,47		
I feel that I have achieved the goals set together with my facilitator or my care companion	0,41		
I feel that I have received enough information about the program		0,96	
The length of the sessions was not too long		0,81	
I feel that I have received enough information about SMART2D		0,60	
It has been easy and effortless to have the sessions on phone		0,50	
I have spent less time with my family/friends due to participation in the program			0,81
I have changed my schedule to be able to participate in the coaching sessions			0,76
Eigenvalue	5,8	3,7	2,0
Variance explained	47%	30%	16%
Cronbach's alpha	0.90	0.77	0.85

Note: Factor loadings < 3 are omitted from the table.

The intervention was perceived as highly acceptable by participants for *Affective attitude and effectiveness* and *Coherence and understanding,* with no significant differences between the diagnostic groups (T2D versus high-risk of T2D). *Perceived burden* was relatively low, although younger participants and those at high-risk perceived the burden as significantly higher compared with the older participants and those with T2D respectively (Table 11).

Table 11. Factor score distribution (median & interquartile range) for the final domains

	Affective attitude and effectiveness Median (IQR)	**Coherence and understanding** Median (IQR)	**Perceived burden** Median (IQR)
Total n = 49	91 (84-100)	100 (81-100)	0 (0-75)
Comparison between diagnostic groups			
Diabetes (n = 19)	87 (84-95)	100 (88-100)	0 (0-0)
High risk (n = 30)	95 (86-100)	100 (81-100)	38 (0-88)
P-value	0.1196	0.7078	0.0036
Comparison between age groups*			
Younger (n = 26)	97 (89-100)	100 (81-100)	38 (0-88)
Older (n = 23)	86 (80-93)	100 (94-100)	0 (0-38)
P-value	0.0066	0.5910	0.0515

IQR: Interquartile range; * Age groups: younger: < median age and older: >/= median age

STUDY 4: INTERACTION AS PART OF THE INTERVENTION DELIVERY PROCESS OF A PREVENTION AND SELF-MANAGEMENT SUPPORT INTERVENTION FOR T2D

In this study we wanted to understand more about the different dimensions of interaction between the facilitator and participant in the delivery of the telephone-facilitated health coaching sessions as part of intervention fidelity.

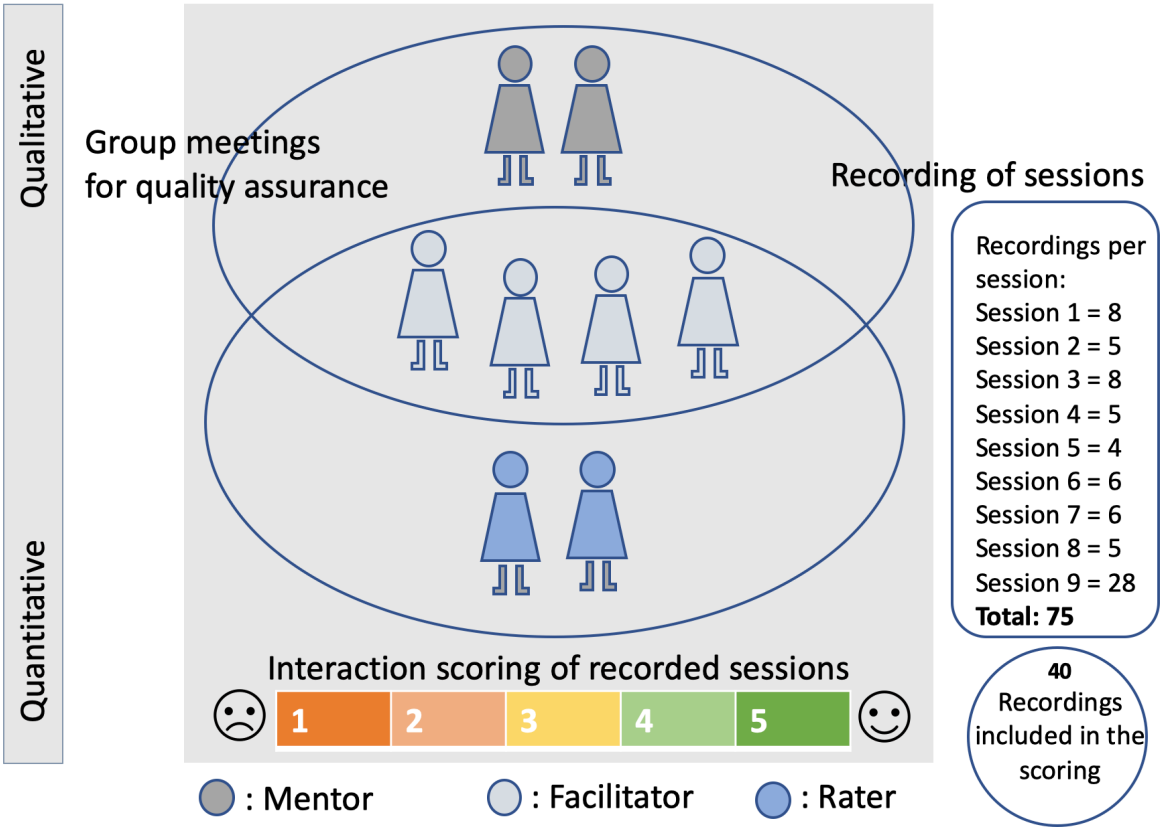

Figure 9. Graphical abstract of study 4

Exploratory factor analysis was conducted to validate the developed interaction tool, resulting in the identification of three domains: 1) Collaborative relationship, 2) Delivery of the intervention content and 3) Strength- based behavior coaching (Table 12).

Table 12. Factor loadings and the Cronbach's alpha for the three domains

Section/ Question		Factor 1 **Collaborative relationship**	Factor 2 **Delivery of intervention content**	Factor 3 **Strength-based behavioral coaching**
s5q4	The session holds a positive atmosphere	0.97		
s5q2	The participant engages with the facilitator during the session	0.89		
s5q1	The participant shows interest in the session	0.83		
s4q1	The facilitator works with the participant to identify his/her strengths	0.58		
s6q7	The facilitator used the session guide to conduct the session		0.83	
s6q3	The facilitator encouraged the participant to work on the sessions specific suggested tasks		0.69	
s6q4	The facilitator encouraged the participant to set goals		0.64	
s6q1	The facilitator informed the participant about the content of the session		0.60	
s6q6	The facilitator demonstrates knowledge pertaining to the content of the session		0.54	
s6q9	The facilitator gave the participant the opportunity to ask questions			0.85
s4q4	The facilitator gives sufficient time for participant reflection and response			0.74
s5q6	The participant shares experiences with the facilitator			0.56
s4q3	The facilitator verbally reflects on participant's talk			0.49
s4q5	The facilitator summarises participant's talk			0.44
	Eigenvalue	5.0	1.7	1.3
	Variance explained	57%	19%	15%
	Cronbach's alpha	0.89	0.83	0.74

Significant differences were found between the four facilitators with respect to the delivery of the intervention (Table 13).

Table 13. Factor score distribution for the final domains (Likert summated scores)

	Collaborative relationship Median (IQR)	**Delivery of intervention content** Median (IQR)	**Strength-based behavioral coaching** Median (IQR)
Total (N=40)	75 (69-81)	81 (76-94)	75 (70-78)
Comparison between facilitators (F)			
F 1 (n=10)	75 (75-81)	94 (85-100)	76 (70-80)
F 2 (n=10)	75 (59-75)	75 (73-75)	70 (65-75)
F 3 (n=12)	78 (72-97)	81 (79-92)	75 (71-80)
F 4 (n= 8)	78 (70-84)	81 (78-90)	73 (70-75)
P-value	0.1465	0.0017*	0.2079

The domains from the quantitative analysis Collaborative relationship, Delivery of the intervention and Strength-based behavioral coaching were developed into themes deductively. In addition, several sub-themes were formed. Differences in the delivery were particularly apparent in two sub-themes of the 'Delivery of the intervention': Goal setting as a process and an outcome and Adaptation and tailoring of support (Figure 10).

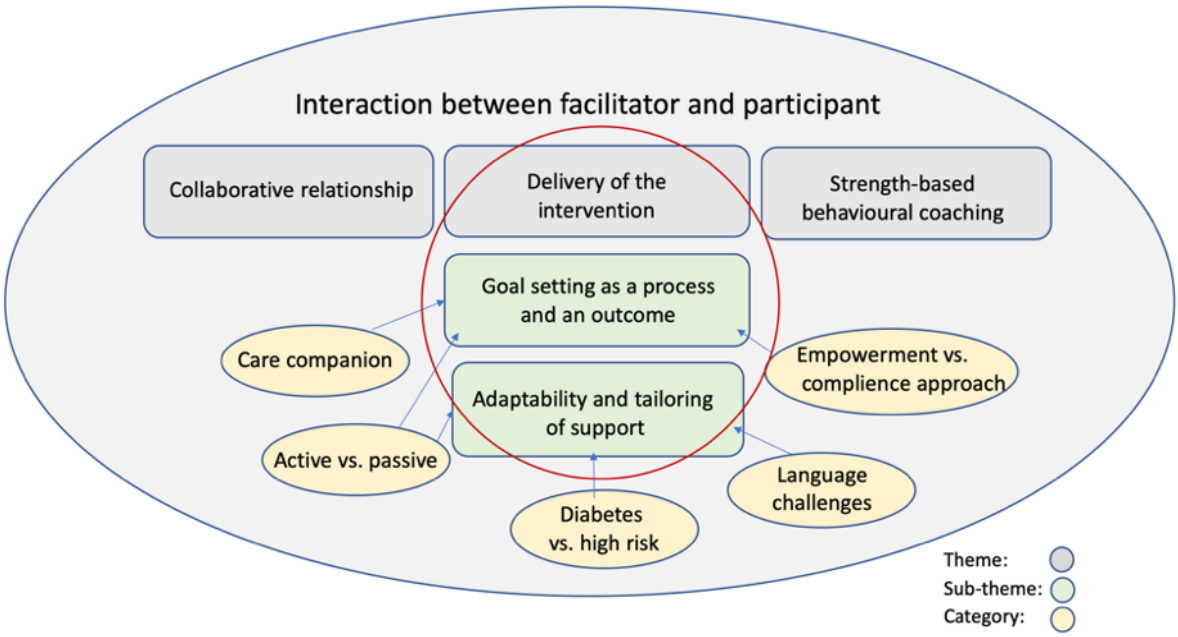

Figure 10. Thematic map showing five of the themes developed in the qualitative analysis.

To illustrate the two sub-themes of 'delivery of the intervention', quotes from the facilitators (F) are presented below.

Goal setting as a process and an outcome

The goal setting process for behavior change was experienced as challenging and approaches for goalsetting varied between the facilitators. For some facilitators goal setting was a central part of the intervention sessions, while for others it was a less straight forward transparent process. Some facilitators promoted certain behaviors by suggesting ideas and giving participants time to reflect on them. This was expressed as a way to encourage participants to set up goals for themselves:

F3: I think that the whole idea of suggesting things to them and letting them reflect upon them is a good one. (…) Sometimes people think that they've done it all and there is nothing more. This is the thing when you have a situation for them to reflect and that is the situation I'm talking about. So, when they start reflecting upon, I mean upon it then you know an idea pops up and it becomes a goal.

The facilitators both suggested activities and built on suggestions coming from the participants to identify measurable behaviors:

F1: But for my understanding of this, we have suggestions for inspiration, so I always think of what's the objective behind giving someone a suggestion. So, your main goal is that maybe this person will take it. You think it is a good idea and then you will convince them, right. So, if I give them the inspiration, the success, my 100 percent success is when they are saying, oh, that's a good idea, I will do that. That's how I see it.

Participants were encouraged to seek support from a close friend or partner, referred to as a care companion. In accordance with the SMART2D session structure, the goals were supposed to be set together with the care companions. All facilitators expressed concerns about the involvement of the care companion in goal setting and they used different strategies. Many of the participants expressed no need for an additional care companion since they were having the facilitator as their social support component. The importance of goalsetting also differed depending on the type of participant, where goal setting was perceived as more important for the less active participants, and less important for already active participants, although it was perceived easier to set goals for the active participants.

Adaptability and tailoring of support

Tailoring the intervention to meet participants' needs was considered necessary and important, and the facilitators expressed that every session should be tailored to each participant. The sessions needed to be delivered at different timepoints to suit the participants' routine. A main difference between persons at risk of developing diabetes and the ones with T2D was that in general participants with T2D had more knowledge on recommendations for lifestyle modification as they had previously received lifestyle counselling from diabetes nurses at the PHCCs. The facilitators talked about the participants in terms of active versus non-active. Participants with already active lives seemed easier to engage in intervention activities.

Many of the participants seemed to have a need for social contact and sometimes the facilitators felt their function was more general social support than a specific support for diabetes prevention and management. There were examples of participants expressing feelings of loneliness. The participants developed a personal relationship with the participants and that strengthened their motivation:

F3: I think there is also a general feeling that the participants know there is somebody who is looking out for them to you know, to change. Because I had the experience of one person who said: "You know I really understand my situation and I need to change my behavior because I'm not happy I feel overweight and obese and all that. But since you called me, I have more motivation to you know, to go and exercise and to walk and to change my meals. So, I'm looking forward to these phone calls."

Language was a challenge as Swedish was not the first language of many participants or all facilitators. The coaching was offered in 'easy Swedish' (without technical and complicated medical terms), English, Spanish, Arabic and Somali, but language skills varied. Participants with limited language skills were offered an interpreter, although this was not preferred by any of the participants. In some cases the participants instead got help from their spouses or relatives.

F3: So, I have one where the man is the one who actually takes the calls, and the woman is there. And the woman is the participant. He is the care companion, but he is the one who takes the calls because she has a little bit of a problem with Swedish.

In the quantitative results differences between facilitators were found in the delivery (Table 13), which was further confirmed by the subsequent qualitative analysis. Thus, the qualitative results added an explanation to the differences observed from the quantitative results.

7 DISCUSSION

This PhD project aimed to understand the feasibility of implementing a self-management support intervention in socioeconomically disadvantaged areas in Stockholm. From this research we found that the risk of developing T2D in and of itself does not motivate behavior change and that different diabetes screening approaches are needed to reach persons at risk in disadvantaged settings. Although the implementation process of individually targeted lifestyle interventions such as the SMART2D project is complex, this study showed that telephone-facilitated health coaching was found feasible for participants in disadvantaged areas of Stockholm.

This research project engaged both the intervention participants and the persons involved in networks around them, leading to self-management support beyond the formal health care system. These findings will be discussed in relation to the Expanded Chronic Care Model (ECCM) [106] (Figure 1).

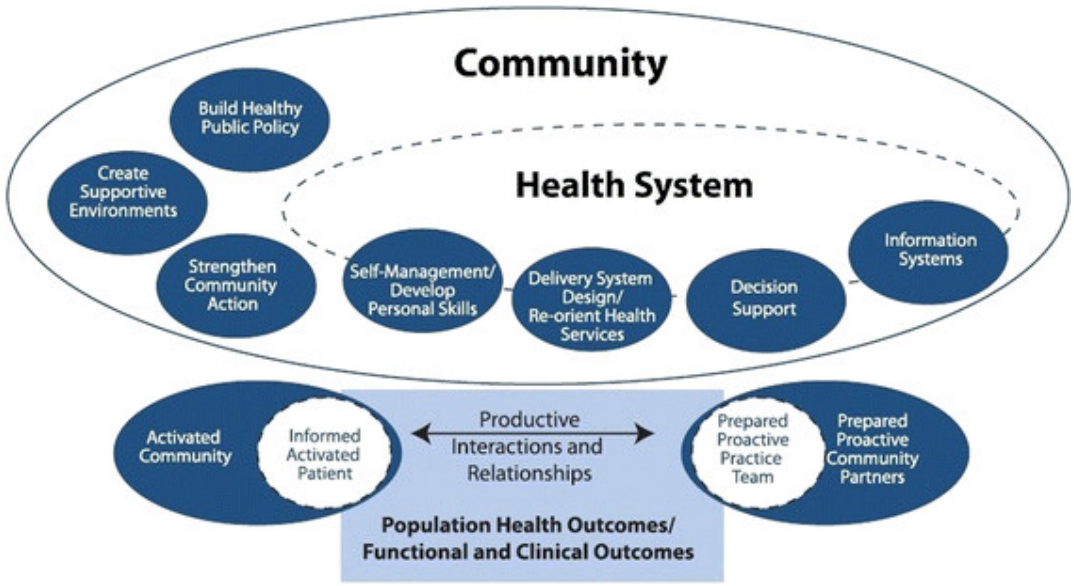

Figure 1. The Expanded chronic care model developed by Barr et al. [106].

Study 1 showed that the concept of reversibility was not clear to the participants. Seen from the ECCM, improving communication by clarifying the concept of reversibility [26, 27] would lead to more *informed* and *activated patients* in *self-management and development of personal skills*.

Implementation of community screening fits well in the ECCM. Expanding health care is necessary to reach out to the community outside of the health care system, where persons at risk of T2D or with undiagnosed T2D can be detected at health facilities when they seek care for other reasons. The implementation of community screening *activates the community* and *strengthens the community action*. It might potentially also lead to a *re-orientation of the health system*. In the ECCM a lifestyle intervention such as the SMART2D telephone-facilitated health coaching is about *self-management/development of personal skills*, which leads to *informed and activated participants*. The social support component in terms of introducing the concept of a care companion is part of *creating supportive environments* and by expanding the self-management to include the care companions, this extension *activates the community*. To implement support for diabetes prevention and management outside of the traditional health care, such as the SMART2D intervention, would be a *re-orientation of the health system* which would *activate the community* and *strengthen the community action.*

PREDIABETES AND ITS POTENTIAL FOR REVERSIBILITY

Many participants in study 1 understood their risk status differently compared to how it was intended by the Stockholm Diabetes Prevention Program. This is in line with other literature showing that scientific statistical knowledge can be difficult to translate to the clinical situation of individuals [174] and that misinterpretations are common between health care providers and patients [175]. A reason for misinterpretation may be that health care providers do not want to worry the patients unnecessarily [175].

Diagnoses were reported as triggers for behavior change, in the same manner as another study reported that the lack of a clear diagnosis did not facilitate changes in lifestyle [176]. In addition, partners' diagnoses influenced the participants to modify their lifestyle, in particularly to conduct dietary changes, which is in line with other evidence showing that social environment influences positive food changes [177, 178].

A problem with communicating risk status could be that prediabetes is not seen as a "real diagnosis" but a condition with an uncertainty of the disease development. As seen in study 1, the perceived risk differed between individuals according to their overall perspective on risk, which is reflected in their willingness to change their lifestyle. The "real diagnoses" were the ones that led to action in terms of lifestyle modification efforts. From this perspective the information about prediabetes should be communicated as a serious condition to trigger lifestyle modification. At the same time, there could be a risk in that the information about a serious risk would prolong the actual period of illness [64].

DIABETES SCREENING APPROACHES TO REACH PERSONS AT HIGH RISK OF T2D

In study 2 community screening was shown to be in particularly effective in reaching persons who are often not reached by health facilities; they were in particular from non-European countries, mostly in Africa and Asia. Community screening has been found effective in reaching high-risk populations not reached by ordinary care [41, 42]. On the other hand, to follow up and care for persons identified as having the particular condition screened for is a challenge as persons are often lost in the referral process [179]. This is different compared to health care centers that have the capacity to add the information about risk status in the patient register and refer patients for further care when needed. A collaboration between community screening initiatives and health facilities can possibly overcome this issue.

Screening tests create opportunities to act on risk information [62, 180], although there could be a risk in informing persons about their risk of developing diabetes when they are falsely classified as having a condition. i.e. being overdiagnosed [36, 38, 181]. Overdiagnosis may result in anxiety, reduced quality of life and unnecessary treatments [38], which may be both harmful and costly [182]. Although not many, there were examples of participants in study 1 that reacted on their risk status as sickening [65] and almost shaped a sufferer's identity [64] related to being at risk, which could be interpreted as a result of overdiagnosing risk status.

TELEPHONE-FACILITATED HEALTH COACHING AS AN ACCEPTABLE LIFESTYLE INTERVENTION APPROACH FOR DIABETES PREVENTION AND MANAGEMENT

Acceptability of a lifestyle intervention can be assessed using a questionnaire based on Sekhon's Theoretical Framework of Acceptability (TFA). The SMART2D intervention was concluded acceptable for the target group, persons with T2D or at high risk of developing T2D. Even though the telephone coaching was found acceptable, some participants might have preferred in-person coaching as has been the case for participants in another study on telephone coaching [183].

Although the perceived burden of working with behavioral change remained relatively low among all participants, younger individuals and those at high-risk showed a higher perceived burden compared to older individuals and those with T2D. Other research has shown higher participation numbers for older compared to younger participants in lifestyle interventions for diabetes prevention [184, 185]. This could be due to higher perceived burden among the younger participants. Older participants are also more likely to have higher self-monitoring rates and adherence for taking medication [184, 186], while younger participants have poorer glucose control [187]. In addition, younger persons with early onset of T2D have a higher prevalence of clinical and behavioral risk factors such as physical inactivity, obesity and tobacco smoking [187]. Lifestyle interventions that especially target younger participants at high risk of developing T2D are therefore needed.

In the qualitative analysis of study 4 the facilitators reported that participants with a T2D diagnosis were more familiar with lifestyle recommendations suggested by the SMART2D team due to previous contacts with the diabetes nurses from the PHC. This could be an explanation as to why the burden of participation in the lifestyle intervention was perceived as higher for the high-risk participants. However, the capacity for preventive care is limited within the PHC and fragmentation of health care institutions has been identified as a problem within Swedish health care, with its lack of collaboration with community networks [118, 156]. To reach and inform persons at high risk of T2D, interventions outside the health care settings are needed. This requires active collaboration between stakeholders.

SOCIAL SUPPORT FOR MAKING AND MAINTAINING CHANGES TOWARDS A HEALTHIER LIFESTYLE

Social support is important for diabetes self-management [119] and peer support has positive effects on behaviour change [119, 125, 188]. This was reflected in the partner's influence on habitual changes in relation to diet in study 1, which is in line with other research showing that social networks influence food choices [189]. The positive effects of social support are well recognized [119, 125, 188]. The SMART2D intervention integrated a social component in terms of encouragement to include a care companion (peer/friend/family member/other person in the participants close network) in the suggested healthy lifestyle activities. In study 4 the intervention facilitators reported that the participants expressed no need for involving other persons in their social network in the program. Although there were good examples of couples where the concept of working together with a care companion worked well, these were described as exceptions. The lack of need for an additional social component for the intervention participants could have been because the facilitator functioned as their care companion. To establish a care companion relationship with someone in the participants' close network is a more sustainable solution since the facilitators could only provide support during the intervention period.

IMPLEMENTATION OF LIFESTYLE INTERVENTIONS IN SOCIOECONOMICALLY DISADVANTAGED AREAS

Tailoring of the intervention to the participants' needs was challenging with regards to following the intervention guide. In addition, the language barrier was a hindering factor identified in the lifestyle coaching provided. Although SMART2D tried to solve this by using language skilled facilitators for some patients, the 'easy Swedish' used by both participants and facilitators who tried to tailor the intervention to the participants was not always optimal in the intervention delivery. For a less challenging support process, language skilled facilitators are needed in the delivery of interventions aiming to prevent and manage diabetes.

A critique of individually targeted lifestyle interventions such as SMART2D is the risk of blaming individuals for making bad lifestyle choices and creating poor health outcomes instead of focusing on structural problems [21, 85, 86]. From this perspective, interventions on a more

structural level such as changing the food environment in a community avoids the blaming of the individual for their lifestyle choices, and may still lead to changes in diet. To focus on improving the structural conditions that lead to a decrease of the underlying causes may also give greater and more long-term effects than lifestyle interventions targeting individuals. At the same time, there are examples of individually targeted lifestyle interventions leading to reduction of anxiety, stress and depression in socioeconomically disadvantaged women [80], and it can be assumed that this affects the children and their disease development throughout the life-course. From a life-course perspective [190], focusing on good schools and educational opportunities are most likely strategies that would give positive long-term health improvements and would reduce diabetes risk and prevalence in socioeconomically disadvantaged areas.

Different aspects of diabetes risk are related to social determinants of health [3, 5, 7, 18] and diabetes risk is hard to prioritize by an individual when that person has more urgent needs to address. From informal discussions with persons I met during time spent in the field, economy was talked about as a hindering factor for making healthy lifestyle choices, which is in line with a qualitative study conducted in the same setting reporting on T2D as only one of many social problems requiring attention [118]. Similarly, patients with T2D in socioeconomically disadvantaged settings have reported that lifestyle advice is hard to follow when they have other diagnoses that are hindering them from adhering to the recommendations [191]. T2D is seen as a lifestyle disease, but it mostly affects persons with few lifestyle choices [21]. As shown in a study by Fritzell et al., higher income levels for low income families would reduce ill health in the Swedish context [192]. To reduce unemployment rates in order to increase income levels would therefore be a good strategy for health improvements in these areas where household incomes are low.

Policies are needed to improve the overall health in these areas. Interestingly, there are examples of an increase in the health inequity gap by implementing health policies, where one explanation could be that higher SES groups are more responsive to lifestyle advice [193]. It is therefore a paradox in focusing on disadvantaged areas because not all people are poor or have poor health on an individual level. There can therefore be as Mackenbach (2012) describes it a risk in that the more well-off individuals benefit more from the improvements than persons worse off healthwise who are at greater need. This would be an argument for targeting individuals at high-risk of developing T2D as is done by the SMART2D intervention. From the perspective of 'focusing on people in poverty only', as long as health improves for disadvantaged people it can be seen as a success even if the health divide may increase [190]. Since there is an agreement that inequity needs to be reduced on all levels from local contexts to global comparisons, greater efforts are needed. Therefore, both population-wide strategies and interventions targeting individuals are needed and should be combined. Also, we should work actively to reduce segregation in order to avoid areas from becoming and remaining socioeconomically disadvantaged suburbs for many reasons, one being that living in a disadvantaged area is negatively associated with decreased life expectancy and poor health [78].

METHODOLOGICAL CONSIDERATIONS

The participants in study 1 expressed that they appreciated the risk information and stated that this gave them the opportunity to make lifestyle modifications. At the same time, very few of them made changes because of the risk of developing T2D. Here a potential social desirability bias [194] could have been a reason for the positive answers. Social desirability bias could also have led to more positive answers in study 3, where the acceptability tool was administered by the SMART2D project that implemented the intervention. However, to minimize this bias a research assistant who was unfamiliar to the participants administered the survey. The participants who answered the survey also had a higher number of intervention contacts compared to non-participants. Also, the drop-out rate from the survey was relatively high. This could indicate that the participants were in general more positive to the intervention compared with those who discontinued the intervention. It would therefore have been valuable to conduct qualitative interviews to understand how participants who discontinued the intervention viewed the intervention and its acceptability.

A limitation of study 1 is that all participants were born in Sweden and are thus not the same population as in other studies within this research project, nor are they representative of the total population in Stockholm. Therefore, the transferability of study 1 may be limited to similar settings. Another limitation of this study is that we did not have access to actual phone conversations between health providers and participants when the results from the SDPP examinations were communicated. Therefore, it is not possible to know how risk information was communicated to the participants. This could have affected the trustworthiness of the data. There could also have been recall bias [195-197] since the participants were asked to describe changes in lifestyle over a ten-year period.

The screenings in study 2 were carried out in similar socioeconomically disadvantaged areas. However, the sites could not be completely matched in every respect. Also, the same risk assessment tool FINDRISC was used in both screening approaches. For this study it was decided to use the cut-off ≥12. Cut-offs between 11 and 14 have been considered to generate acceptable sensitivity and specificity in different population groups [54, 198]. At the facility-based screenings the FINDRISC was offered to all persons in the waiting rooms at PHCCs. In addition, the health care personnel referred patients they thought were at risk of developing T2D to conduct the FINDRISC scoring. This could not be completely avoided and may have contributed to a biased sample.

The 5 point Likert scale format used in study 3 and 4 is preferred to 7 or 11 point scales [199]. However, one risk in agree-disagree scales is that it is more common for participants to agree than disagree with the statement offered regardless of its content [200, 201], leading to acquiescence response bias. This could have been the case in our study as well.

A limitation of the qualitative part of study 4 is that the data were only from the facilitators' perspective. Interviews with participants would have been valuable to understand more of the

challenges and potential improvements for this type of intervention. Another limitation of this study is that sessions conducted by skilled language facilitators in Somali and Arabic were not included in the analysis. Furthermore, the sample sizes were relatively small in both study 3 (n=49) and the quantitative part of study 4 (n=40). It would therefore be interesting to see if the results remained the same with larger study samples.

8 CONCLUSIONS

This thesis showed that communication of diabetes risk is complex and diabetes risk was not perceived as urgent enough to act upon without external triggers. Thus, the potential of reversing diabetes and prediabetes are to be emphasized and more clearly defined in order to serve as motivators for lifestyle modification. Diabetes screening for early detection and an implemented telephone-facilitated support intervention for diabetes management and prevention were feasible in socioeconomically disadvantaged areas of Stockholm. Community screening and facility-based screening were complementary methods, reaching different population groups at high risk of developing diabetes. Community screening in particular reached more hard-to-reach groups with unfavorable risk profiles, making it a critical strategy for T2D prevention. A collaboration between community organizations and primary care is crucial for preventive strategies.

The telephone-facilitated support intervention was found to be acceptable, yet the perceived burden was higher among younger individuals and those at high-risk compared to older individuals and those with T2D respectively. Moreover, an assessment of the interaction between facilitators and participants revealed differences in the delivery styles, in particular relating to the aspect of goalsetting. Further tailoring of the intervention to meet differential participant needs and more focused training on key aspects such as goal setting would be critical in the further testing or implementation of this intervention for optimizing prevention and management of T2D in socioeconomically disadvantaged population groups.

9 POINTS OF PERSPECTIVE

The chronic care models and the ECCM in particular have pointed to the need to see the community as an important part of chronic disease prevention and management. In line with the ECCM, this doctoral project has confirmed that an expansion of chronic care is needed to target persons at risk of T2D outside of traditional health care settings. Preventive strategies such as implementation of community screening and self-management support for persons at high risk of T2D are crucial for decreasing the rising diabetes prevalence.

Prediabetes is a condition that requires more attention. The findings highlight the need to focus on persons at risk of developing diabetes and the lack of lifestyle advice and tools for reversing their diabetes risk. The possibility of reversing elevated glucose values to normal has considerable potential to alleviate the burden of diabetes. This underlines the need to provide support directly in the communities. Given that resources for preventive strategies currently are scarce in primary health care, additional resources should be allocated to initiatives that seek collaboration between community-based organizations and the health care system. Policies for collaborations between primary care and community-based support would strengthen the overall capacity for chronic disease prevention and management, and it would minimize loss to follow-up during the referral process for persons at risk.

Risk communication also needs to be improved. The risk of developing diabetes and associated complications needs to be clearly communicated as a serious health condition and the possibility of reversibility should be emphasized. This should be balanced against the risk of overdiagnosis and causing harm, such as stress and anxiety. Therefore, it is important to not only inform, but also provide the tools and support needed for managing and reducing diabetes risk.

Intercultural health care is needed for diabetes prevention and management in multicultural healthcare settings. Tailoring the coaching was emphasized as an important aspect in the support process, which is both in line with intercultural competence and patient centered counselling. Language skilled facilitators are to be considered in lifestyle counselling situations. Research on what sort of interventions would attract younger participants for a less burdensome support approach would be valuable.

Support for diabetes prevention and management is particularly urgent to implement in socioeconomically disadvantaged areas where the T2D prevalence and risk is high. Since there is a considerably higher prevalence of T2D in socioeconomically disadvantaged areas of Stockholm than in the Stockholm as a whole, and Sweden in total, it is also important to implement structural interventions to improve the overall health in these areas. As other countries in Europe and beyond face similar problems in diabetes detection, prevention and management, this Swedish case may well serve as an example within a broader global context.

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11 REFERENCES

1. International Diabetes Federation. *IDF Diabetes Atlas*. 2019 [cited 2019 December]; 9:[Available from: https://diabetesatlas.org/en/sections/proven-and-effective-actions.html.
2. World Health Organization, *Global status report on non communical diseases*. 2014: Geneva.
3. Puckrein, G.A., B.M. Egan, and G. Howard, *Social and medical determinants of cardiometabolic health: the big picture.* Ethnicity & disease, 2015. 25(4): p. 521.
4. Osborn, C.Y., M. de Groot, and J.A. Wagner, *Racial and ethnic disparities in diabetes complications in the northeastern United States: the role of socioeconomic status.* Journal of the National Medical Association, 2013. 105(1): p. 51-58.
5. Engelen, L., et al., *Who is at risk of chronic disease? Associations between risk profiles of physical activity, sitting and cardio-metabolic disease in Australian adults.* Australian and New Zealand Journal of Public Health, 2017. 41(2): p. 178-183.
6. Mendenhall, E., *Syndemic Suffering in Soweto: Violence and Inequality at the Nexus of Health Transition in South Africa.* Annals of Anthropological Practice, 2014. 38(2): p. 300-316.
7. Mendenhall, E., et al., *Speaking through Diabetes.* Medical Anthropology Quarterly, 2010. 24(2): p. 220-239.
8. Montesi, L., *"Como Si Nada": Enduring Violence and Diabetes among Rural Women in Southern Mexico.* Medical anthropology, 2018. 37(3): p. 206-220.
9. Mendenhall, E., *Beyond Comorbidity: A Critical Perspective of Syndemic Depression and Diabetes in Cross-cultural Contexts.* Med Anthropol Q, 2015.
10. Shoenberg, D., Stoller, Kart, *Situating Stress: Lessons from Lay Discourses on Diabetes*, in *Anthropology and Public Health - Bridging Differences in Culture and Society*, I.M. Hahn R., Editor.
11. Tabák, A.G., et al., *Prediabetes: a high-risk state for diabetes development.* The Lancet, 2012. 379(9833): p. 2279-2290.
12. Dhippayom, T., N. Chaiyakunapruk, and I. Krass, *How diabetes risk assessment tools are implemented in practice: a systematic review.* Diabetes research and clinical practice, 2014. 104(3): p. 329-342.
13. Bowen, M., *Rethinking diabetes screening and case finding strategies in clinical practice: who's really at risk?* 2016.
14. Herman, W.H., et al., *Early detection and treatment of type 2 diabetes reduce cardiovascular morbidity and mortality: a simulation of the results of the Anglo-Danish-Dutch Study of Intensive Treatment in People With Screen-Detected Diabetes in Primary Care (ADDITION-Europe).* Diabetes care, 2015. 38(8): p. 1449-1455.
15. Simmons, D. and J.C. Zgibor, *Should we screen for type 2 diabetes among asymptomatic individuals? Yes.* Diabetologia, 2017. 60(11): p. 2148-2152.

16. Wiedman, D., *Native American embodiment of the chronicities of modernity: reservation food, diabetes, and the metabolic syndrome among the Kiowa, Comanche, and Apache.* Med Anthropol Q, 2012. 26(4): p. 595-612.

17. Walker, C.G., et al., *Modelling the Interplay between Lifestyle Factors and Genetic Predisposition on Markers of Type 2 Diabetes Mellitus Risk.* PloS one, 2015. 10(7): p. e0131681.

18. Brown, A.F., et al., *Socioeconomic position and health among persons with diabetes mellitus: a conceptual framework and review of the literature.* Epidemiologic reviews, 2004. 26(1): p. 63-77.

19. International Diabetes Federation, *Global Diabetes Plan 2011-2021*.

20. Bombak, A.E., et al., *A systematic search and critical thematic, narrative review of lifestyle interventions for the prevention and management of diabetes.* Critical Public Health, 2020. 30(1): p. 103-114.

21. Manderson, L., *"Lifestyle" disease on the margins.* American Anthropologist, 2020. 122(3): p. 662-663.

22. Browne, J.L., et al., *'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes.* BMJ open, 2013. 3(11).

23. Association, A.D., *Classification and diagnosis of diabetes: standards of medical care in diabetes—2019.* Diabetes Care, 2019. 42(Supplement 1): p. S13-S28.

24. Alvarsson, M., A. Hilding, and C.G. Östenson, *Factors determining normalization of glucose intolerance in middle-aged Swedish men and women: a 8–10-year follow-up.* Diabetic Medicine, 2009. 26(4): p. 345-353.

25. Glechner, A., et al., *Effects of lifestyle changes on adults with prediabetes: a systematic review and meta-analysis.* Primary care diabetes, 2018.

26. Taylor, R., *Type 2 diabetes: etiology and reversibility.* Diabetes care, 2013. 36(4): p. 1047-1055.

27. Ang, G.Y., *Reversibility of diabetes mellitus: Narrative review of the evidence.* World journal of diabetes, 2018. 9(7): p. 127.

28. Lean, M.E., et al., *Primary care-led weight management for remission of type 2 diabetes (DiRECT): an open-label, cluster-randomised trial.* The Lancet, 2018. 391(10120): p. 541-551.

29. Leslie, W.S., et al., *The Diabetes Remission Clinical Trial (DiRECT): protocol for a cluster randomised trial.* BMC family practice, 2016. 17(1): p. 20.

30. Gregg, E.W., et al., *Association of an intensive lifestyle intervention with remission of type 2 diabetes.* Jama, 2012. 308(23): p. 2489-2496.

31. Mottalib, A., et al., *Diabetes remission after nonsurgical intensive lifestyle intervention in obese patients with type 2 diabetes.* Journal of diabetes research, 2015. 2015.

32. Steven, S., et al., *Reversal of Type 2 diabetes after bariatric surgery is determined by the degree of achieved weight loss in both short-and long-duration diabetes.* Diabetic Medicine, 2015. 32(1): p. 47-53.

33. Lingvay, I., et al., *Rapid improvement in diabetes after gastric bypass surgery: is it the diet or surgery?* Diabetes care, 2013. 36(9): p. 2741-2747.

34. Colagiuri, S., *Epidemiology of prediabetes.* Medical Clinics, 2011. 95(2): p. 299-307.

35. Yudkin, J.S. and V.M. Montori, *The epidemic of pre-diabetes: the medicine and the politics.* Bmj, 2014. 349: p. g4485.

36. Hofmann, B., *Back to basics: overdiagnosis is about unwarranted diagnosis.* American Journal of Epidemiology, 2019.

37. Genuth, S., et al., *Follow-up report on the diagnosis of diabetes mellitus.* Diabetes Care, 2003. 26(11): p. 3160-7.

38. Hofmann, B., *Diagnosing overdiagnosis: conceptual challenges and suggested solutions.* European journal of epidemiology, 2014. 29(9): p. 599-604.

39. Chatterjee, R., et al., *Screening for diabetes and prediabetes should be cost-saving in patients at high risk.* Diabetes Care, 2013. 36(7): p. 1981-1987.

40. Gillies, C.L., et al., *Different strategies for screening and prevention of type 2 diabetes in adults: cost effectiveness analysis.* Bmj, 2008. 336(7654): p. 1180-1185.

41. Shahim, B., et al., *Effectiveness of different outreach strategies to identify individuals at high risk of diabetes in a heterogeneous population: a study in the Swedish municipality of Södertälje.* European journal of preventive cardiology, 2018. 25(18): p. 1990-1999.

42. Davidson, M.B., P. Duran, and M.L. Lee, *Community Screening for Pre-Diabetes and Diabetes Using HbA1c Levels in High Risk African Americans and Latinos.* Ethnicity & disease, 2014. 24(2): p. 195.

43. Millard, A.V., et al., *Diabetes screening and prevention in a high-risk, medically isolated border community.* Frontiers in Public Health, 2017. 5: p. 135.

44. Misra, R., et al., *Community-based diabetes screening and risk assessment in rural West Virginia.* Journal of diabetes research, 2016. 2016.

45. Man Ying Lee, C. and S. Colagiuri, *Population approaches for detecting glucose disorders.* Current diabetes reviews, 2016. 12(1): p. 42-50.

46. Engebretson, J., J.S. Mahoney, and G. Walker, *Participation in community health screenings: a qualitative evaluation.* Journal of community health nursing, 2005. 22(2): p. 77-92.

47. Feldman, A.L., et al., *Screening for type 2 diabetes: do screen-detected cases fare better?* Diabetologia, 2017. 60(11): p. 2200-2209.

48. Simmons, R.K., et al., *Effect of population screening for type 2 diabetes and cardiovascular risk factors on mortality rate and cardiovascular events: a controlled trial among 1,912,392 Danish adults.* Diabetologia, 2017. 60(11): p. 2183-2191.

49. Saffar, D., et al., *Screening for diabetes in an African American community: Identifying characteristics associated with abnormal blood glucose readings.* Journal of the National Medical Association, 2011. 103(3): p. 190-193.

50. Simmons, R., et al., *Do simple questions about diet and physical activity help to identify those at risk of Type 2 diabetes?* Diabetic medicine, 2007. 24(8): p. 830-835.

51. Mavrogianni, C., et al., *Evaluation of the Finnish Diabetes Risk Score as a screening tool for undiagnosed type 2 diabetes and dysglycaemia among early middle-aged adults in a large-scale European cohort. The Feel4Diabetes-study.* Diabetes Research and Clinical Practice, 2019. 150: p. 99-110.

52. Hellgren, M., et al., *Feasibility of the FINDRISC questionnaire to identify individuals with impaired glucose tolerance in Swedish primary care. A cross-sectional population-based study.* Diabetic Medicine, 2012. 29(12): p. 1501-1505.

53. Saaristo, T., et al., *Cross-sectional evaluation of the Finnish Diabetes Risk Score: a tool to identify undetected type 2 diabetes, abnormal glucose tolerance and metabolic syndrome.* Diabetes and vascular disease research, 2005. 2(2): p. 67-72.

54. Jølle, A., et al., *Validity of the FINDRISC as a prediction tool for diabetes in a contemporary Norwegian population: a 10-year follow-up of the HUNT study.* BMJ Open Diabetes Research and Care, 2019. 7(1).

55. Zhang, L., et al., *Evaluation of Finnish Diabetes Risk Score in screening undiagnosed diabetes and prediabetes among US adults by gender and race: NHANES 1999-2010.* PloS one, 2014. 9(5): p. e97865.

56. Khunti, K., et al., *Systematic review and meta-analysis of response rates and diagnostic yield of screening for type 2 diabetes and those at high risk of diabetes.* PloS one, 2015. 10(9): p. e0135702.

57. Grant, T., et al., *Community-based screening for cardiovascular disease and diabetes using HbA1c.* American journal of preventive medicine, 2004. 26(4): p. 271-275.

58. Hellgren, M., K.H. Steiner, and L. Bennet, *Haemoglobin A1c as a screening tool for type 2 diabetes and prediabetes in populations of Swedish and Middle-East ancestry.* Primary care diabetes, 2017. 11(4): p. 337-343.

59. Sequeira, I. and S. Poppitt, *HbA1c as a marker of prediabetes: a reliable screening tool or not?* 2017.

60. Barry, E., et al., *Efficacy and effectiveness of screen and treat policies in prevention of type 2 diabetes: systematic review and meta-analysis of screening tests and interventions.* Brittish Medical Journal,, 2017. 356: p. i6538.

61. Slovic, P., et al., *Risk as analysis and risk as feelings: Some thoughts about affect, reason, risk, and rationality.* Risk Analysis: An International Journal, 2004. 24(2): p. 311-322.

62. Andersen, J.H. and S.R. Whyte, *Measuring risk, managing values: health technology and subjectivity in Denmark.* Anthropology & medicine, 2014. 21(3): p. 265-276.

63. Linell, P., et al., *Expert Talk in Medical Contexts: Explicit and Implicit Orientation to Risks.* Research on Language & Social Interaction, 2002. 35(2): p. 195-218.

64. Smith-Morris, C., *The chronicity of Life, the Acuteness of diagnosis*, in *Chronic conditions, fluid states : chronicity and the anthropology of Illness*, M.L.S.-M. C., Editor. 2010, Rutgers University Press: New Brunswik. p. 21-37.

65. Sachs, L., *Is there a pathology of prevention? The implications of visualizing the invisible in screening programs.* Culture, medicine and psychiatry, 1995. 19(4): p. 503-525.

66. Willems S, D.M.S., Deveugele M, Derese A, De Maeseneer J., *Socio-economic status of the patient and doctor-patient communication: does it make a difference?* Patient Education and Counseling 56 (2005) 139–146, 2005. 56: p. 139-146.

67. White, R.O., et al., *Perceptions of provider communication among vulnerable patients with diabetes: influences of medical mistrust and health literacy.* Journal of health communication, 2016. 21(sup2): p. 127-134.

68. Ciechanowski, P.S., et al., *The patient-provider relationship: attachment theory and adherence to treatment in diabetes.* American Journal of Psychiatry, 2001. 158(1): p. 29-35.

69. Simpson, M.e.a., *Doctor patient communication: The Toronto consensus.* BMJ, 1991. 303(1385-1387).

70. Parker PA, D.B., Tishelman C, Brundage MD, *What do we know about facilitating patient communication in the cancer care setting?* Psycho-Oncology, 2005. 14(10): p. 848–858.

71. van der Heide, I., et al., *Associations among health literacy, diabetes knowledge, and self-management behavior in adults with diabetes: results of a dutch cross-sectional study.* Journal of health communication, 2014. 19(sup2): p. 115-131.

72. Juul, L., G. Rowlands, and H.T. Maindal, *Relationships between health literacy, motivation and diet and physical activity in people with type 2 diabetes participating in peer-led support groups.* Primary care diabetes, 2018. 12(4): p. 331-337.

73. Vandenbosch, J., et al., *The impact of health literacy on diabetes self-management education.* Health education journal, 2018. 77(3): p. 349-362.

74. Mayberry, L.S., et al., *Bridging the digital divide in diabetes: family support and implications for health literacy.* Diabetes technology & therapeutics, 2011. 13(10): p. 1005-1012.

75. Cavanaugh, K., et al., *Association of numeracy and diabetes control.* Annals of internal medicine, 2008. 148(10): p. 737-746.

76. Sobo, E.J., *The culture concept, Cultural competence and the dangers of "Anthro Lite"*, in *Culture and meaning in health services research: a practical field guide*. 2009, Left Coast Press: California. p. 101-122.

77. Cyril, S., et al., *Exploring the role of community engagement in improving the health of disadvantaged populations: a systematic review.* Global health action, 2015. 8(1): p. 29842.

78. Marmot, M., *The Health Gap: The Challenge of an Unequal World*. 2015: Bloomsbury Publishing PLC.

79. Hays, L.M., et al., *Effects of a Community-based Lifestyle Intervention on Change in Physical Activity Among Economically Disadvantaged Adults With Prediabetes.* American Journal of Health Education, 2016. 47(5): p. 266-278.

80. Gilstrap, L.G., et al., *Community-Based Primary Prevention Programs Decrease the Rate of Metabolic Syndrome Among Socioeconomically Disadvantaged Women.* Journal of Womens Health, 2013. 22(4): p. 322-329.

81. Lachance, L., et al., *Community-Based Efforts to Prevent and Manage Diabetes in Women Living in Vulnerable Communities.* Journal of Community Health, 2018. 43(3): p. 508-517.

82. Inglis, V.B., K. Crawford, D., *Why do women of low socioeconomic status have poorer dietary behaviours than women of higher socieconomic status? - A qualitative exploration* Appetite, 2005. 45(3): p. 334-343.

83. Kokanovic, R. and L. Manderson, *Social support and self-management of type 2 diabetes among immigrant Australian women.* Chronic Illness, 2006. 2(4): p. 291-301.

84. Bourgois, P., et al., *Structural vulnerability: operationalizing the concept to address health disparities in clinical care.* Academic medicine: journal of the Association of American Medical Colleges, 2017. 92(3): p. 299.

85. Gálvez, A., *Taking Susto Seriously: A Critique of Behavioral Approaches to Diabetes.* American Anthropologist, 2020. 122(3): p. 651-652.

86. Gálvez, A., M. Carney, and E. Yates-Doerr, *Chronic Disaster: Reimagining Noncommunicable Chronic Disease.* American Anthropologist, 2020. 122(3): p. 639-640.

87. Lorig, K.R., et al., *Effect of a self-management program on patients with chronic disease.* Effective clinical practice: ECP, 2001. 4(6): p. 256-262.

88. Pirbaglou, M., et al., *Personal health coaching as a type 2 diabetes mellitus self-management strategy: a systematic review and meta-analysis of randomized controlled trials.* American Journal of Health Promotion, 2018. 32(7): p. 1613-1626.

89. Egbujie, B.A., et al., *Role of community health workers in type 2 diabetes mellitus self-management: A scoping review.* PloS one, 2018. 13(6): p. e0198424.

90. Lorig, K.R., et al., *Internet-based chronic disease self-management: a randomized trial.* Medical care, 2006: p. 964-971.

91. Dennis, S.M., et al., *Do people with existing chronic conditions benefit from telephone coaching? A rapid review.* Australian Health Review, 2013. 37(3): p. 381-388.

92. Kleinman, A. and P. Benson, *Anthropology in the clinic: the problem of cultural competency and how to fix it.* PLoS medicine, 2006. 3(10): p. e294.

93. Good, M. and S.D. Hannah, *Shattering culture": perspectives on cultural competence and evidence-based practice in mental health services.* Transcultural Psychiatry, 2015. 52(2): p. 198-221.

94. Hjelm, K.G., et al., *Beliefs about health and diabetes in men of different ethnic origin.* Journal of advanced nursing, 2005. 50(1): p. 47-59.

95. Hjelm, K., et al., *Religious and cultural distance in beliefs about health and illness in women with diabetes mellitus of different origin living in Sweden.* International journal of nursing studies, 2003. 40(6): p. 627-643.

96. Ulrey, K.L. and P. Amason, *Intercultural communication between patients and health care providers: An exploration of intercultural communication effectiveness, cultural sensitivity, stress, and anxiety.* Journal of health communication, 2001. 13(4): p. 449-463.

97. Bradby, H., et al., *Undoing the unspeakable: researching racism in Swedish healthcare using a participatory process to build dialogue.* Health research policy and systems, 2019. 17(1): p. 43.

98. Rocque, R. and Y. Leanza, *A systematic review of patients' experiences in communicating with primary care physicians: intercultural encounters and a balance between vulnerability and integrity.* PloS one, 2015. 10(10): p. e0139577.

99. Carpenter-Song, E.A., M.N. Schwallie, and J. Longhofer, *Cultural competence reexamined: critique and directions for the future.* Psychiatric Services, 2007. 58(10): p. 1362-1365.

100. Deardorff, D.K., *Identification and assessment of intercultural competence as a student outcome of internationalization.* Journal of studies in international education, 2006. 10(3): p. 241-266.

101. Fleckman, J.M., et al., *Intercultural competency in public health: a call for action to incorporate training into public health education.* Frontiers in public health, 2015. 3: p. 210.

102. Beach, M.C., et al., *Cultural competency: A systematic review of health care provider educational interventions.* Medical care, 2005. 43(4): p. 356.

103. Wagner, E.H., et al., *A survey of leading chronic disease management programs: are they consistent with the literature?* Managed care quarterly, 1999. 7(3): p. 56-66.

104. Grover, A. and A. Joshi, *An overview of chronic disease models: a systematic literature review.* Global journal of health science, 2015. 7(2): p. 210.

105. Stellefson, M., K. Dipnarine, and C. Stopka, *Peer reviewed: The chronic care model and diabetes management in US primary care settings: A systematic review.* Preventing chronic disease, 2013. 10.

106. Barr, V., et al., *The expanded chronic care model.* Hosp Q, 2003. 7(1): p. 73-82.

107. Lalonde, M., *A new perspective on the health of Canadians (The Lalonde Report).* Ottawa: Minister of Supply and Services Canada, 1974.

108. Captieux, M., et al., *Supported self-management for people with type 2 diabetes: a meta-review of quantitative systematic reviews.* The Lancet, 2017. 390: p. S32.

109. Knowler, W.C., et al., *Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin.* The New England journal of medicine, 2002. 346(6): p. 393-403.

110. Khan, T., S. Tsipas, and G. Wozniak, *Medical care expenditures for individuals with prediabetes: the potential cost savings in reducing the risk of developing diabetes.* Population health management, 2017. 20(5): p. 389-396.

111. Diabetes Prevention Program Research Group, *The 10-year cost-effectiveness of lifestyle intervention or metformin for diabetes prevention: an intent-to-treat analysis of the DPP/DPPOS.* Diabetes care, 2012. 35(4): p. 723-730.

112. Hunt, L.M. and N.H. Arar, *An analytical framework for contrasting patient and provider views of the process of chronic disease management.* Medical Anthropology Quarterly, 2001. 15(3): p. 347-367.

113. Anderson, R.M. and M.M. Funnell, *Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm.* Patient education and counseling, 2005. 57(2): p. 153-157.

114. Anderson, R.M. and M.M. Funnell, *Patient empowerment: myths and misconceptions.* Patient education and counseling, 2010. 79(3): p. 277-282.

115. MacQueen, K.M., et al., *What is community? An evidence-based definition for participatory public health.* American journal of public health, 2001. 91(12): p. 1929-1938.

116. Carpiano, R.M. and P.W. Hystad, *"Sense of community belonging" in health surveys: what social capital is it measuring?* Health & place, 2011. 17(2): p. 606-617.

117. Minkler, M., *Community organizing and community building for health and welfare*. 2012: Rutgers University Press.

118. Al-Murani, F., et al., *Community and stakeholders' engagement in the prevention and management of Type 2 diabetes: a qualitative study in socioeconomically disadvantaged suburbs in region Stockholm.* Global health action, 2019. 12(1): p. 1609313.

119. van Dam, H.A., et al., *Social support in diabetes: a systematic review of controlled intervention studies.* Patient education and counseling, 2005. 59(1): p. 1-12.

120. Rise, M.B., et al., *Making and maintaining lifestyle changes after participating in group based type 2 diabetes self-management educations: a qualitative study.* PLoS one, 2013. 8(5): p. e64009.

121. Silverman, J., et al., *The Value of Community Health Workers in Diabetes Management in Low-Income Populations: A Qualitative Study.* Journal of community health, 2018: p. 1-6.

122. Nielsen, M.H., et al., *To Tell or Not to Tell: Disclosure and Self-Management among Adults with Early-Onset Type 2 Diabetes: A Qualitative Study.* The Open Diabetes Journal, 2020. 10(1).

123. Hjelm, K. and C. Berter, *Dissimilarities in social support as described by Swedish-and foreign-born persons diagnosed with type 2 diabetes and living in Sweden.* Open Journal of Nursing, 2014. 2014.

124. Hjelm, K. and C. Berterö, *Social support as described by Swedish people diagnosed with type 2 diabetes mellitus.* Primary Health Care Research & Development, 2009. 10(1): p. 26-37.

125. Dale, J., S. Williams, and V. Bowyer, *What is the effect of peer support on diabetes outcomes in adults? A systematic review.* Diabetic Medicine, 2012. 29(11): p. 1361-1377.

126. Bauer, M.S., et al., *An introduction to implementation science for the non-specialist.* BMC psychology, 2015. 3(1): p. 1-12.

127. Peters, D.H., et al., *Implementation research: what it is and how to do it.* Bmj, 2013. 347: p. f6753.

128. Damschroder, L.J., *Clarity out of chaos: use of theory in implementation research.* Psychiatry research, 2020. 283: p. 112461.

129. Proctor, E.K., B.J. Powell, and J.C. McMillen, *Implementation strategies: recommendations for specifying and reporting.* Implementation Science, 2013. 8(1): p. 1-11.

130. Proctor, E., et al., *Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda.* Administration and Policy in Mental Health and Mental Health Services Research, 2011. 38(2): p. 65-76.

131. Hohmann, A.A. and M.K. Shear, *Community-based intervention research: Coping with the "noise" of real life in study design.* American Journal of Psychiatry, 2002. 159(2): p. 201-207.

132. Saturni, S., et al., *Randomized controlled trials and real life studies. Approaches and methodologies: a clinical point of view.* Pulmonary pharmacology & therapeutics, 2014. 27(2): p. 129-138.

133. Arain, M., et al., *What is a pilot or feasibility study? A review of current practice and editorial policy.* BMC medical research methodology, 2010. 10(1): p. 67.

134. Orsmond, G.I. and E.S. Cohn, *The distinctive features of a feasibility study: Objectives and guiding questions.* OTJR: occupation, participation and health, 2015. 35(3): p. 169-177.

135. Bowen, D.J., et al., *How we design feasibility studies.* American journal of preventive medicine, 2009. 36(5): p. 452-457.

136. Tickle-Degnen, L., *Nuts and bolts of conducting feasibility studies.* American Journal of Occupational Therapy, 2013. 67(2): p. 171-176.

137. Karolinska Institutet. *SMART2D*. 2019; Available from: http://ki.se/en/phs/smart2d.

138. Absetz, P., et al., *SMART2D—development and contextualization of community strategies to support self-management in prevention and control of type 2 diabetes in Uganda, South Africa, and Sweden.* Translational Behavioral Medicine, 2020. 10(1): p. 25-34.

139. De Man, J., et al., *Diabetes self-management in three different income settings: Cross-learning of barriers and opportunities.* PloS one, 2019. 14(3).

140. Bennet, L., et al., *Ethnicity is an independent risk indicator when estimating diabetes risk with FINDRISC scores: a cross sectional study comparing immigrants from the Middle East and native Swedes.* Primary care diabetes, 2014. 8(3): p. 231-238.

141. Wandell, P.E., A.C. Carlsson, and K.H. Steiner, *Prevalence of diabetes among immigrants in the Nordic countries.* Current diabetes reviews, 2010. 6(2): p. 126-133.

142. Tao W., Bruce D., and B. B. *Områdesskillnader i sjukdomsförekomst Stockholms län 2006–2011*. 2015; Available from: http://dok.slso.sll.se/CES/FHG/Jamlik_halsa/Rapporter/Omradesskillnader-i-sjukdom.pdf.

143. Agardh, E.E., et al., *Burden of type 2 diabetes attributed to lower educational levels in Sweden.* Population Health Metrics, 2011. 9(1): p. 1-8.

144. Agardh, E.E., et al., *Work stress and low sense of coherence is associated with type 2 diabetes in middle-aged Swedish women.* Diabetes care, 2003. 26(3): p. 719-724.

145. Marmot, M. and R.G. Wilkinson, *Psychosocial and material pathways in the relation between income and health: a response to Lynch et al.* Bmj, 2001. 322(7296): p. 1233-1236.

146. Phillimore, J., et al., *Understanding healthcare practices in superdiverse neighbourhoods and developing the concept of welfare bricolage: Protocol of a cross-national mixed-methods study.* BMC international health and human rights, 2015. 15(1): p. 16.

147. Vertovec, S., *Super-diversity and its implications.* Ethnic and racial studies, 2007. 30(6): p. 1024-1054.

148. Ljung, R., et al., *Socioeconomic differences in the burden of disease in Sweden.* Bulletin of the World Health Organization, 2005. 83: p. 92-99.

149. Marmot, M., *Social determinants of health inequalities.* The lancet, 2005. 365(9464): p. 1099-1104.

150. Jansson, S.P., et al., *Prevalence and incidence of diabetes mellitus: a nationwide population-based pharmaco-epidemiological study in Sweden.* Diabetic medicine, 2015. 32(10): p. 1319-1328.

151. Andersson, T., A. Ahlbom, and S. Carlsson, *Diabetes Prevalence in Sweden at Present and Projections for Year 2050.* PloS one, 2015. 10(11): p. e0143084.

152. Socialstyrelsen. *Nationella riktlinjer för diabetesvård*. 2018 [cited 2019 2019]; Available from: https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2018-10-25.pdf.

153. Landsting, S.L. *Viss*. 2015 2018 [cited 2019; Available from: http://www.viss.nu/Handlaggning/Vardprogram/Endokrina-organ/Prediabetes/.

154. Hälso- och sjukvårdsförvaltningen, *Diabetes i primärvården 2013*. 2014.

155. Staff, A., et al., *Patients requests and needs for culturally and individually adapted supportive care in type 2 diabetes patients A comparative study between Nordic and non-Nordic patients in a social economical vulnerable area of Linkoping, Sweden.* Primary Care Diabetes, 2017. 11(6): p. 522-528.

156. *Samordnad vård och omsorg En analys av samordningsutmaningar i ett fragmenterat vård- och omsorgssystem*. 2016, Myndigheten för vård- och omsorgsanalys.

157. Andersson, C., *Challenges of studying complex community health promotion programmes: Experiences from Stockholm diabetes prevention programme*. 2006: Institutionen för folkhälsovetenskap/Department of Public Health Sciences.

158. Malterud, K., V.D. Siersma, and A.D. Guassora, *Sample size in qualitative interview studies: guided by information power.* Qualitative health research, 2016. 26(13): p. 1753-1760.

159. Karolinska Institutet. *Program 4D*. 2017 2018 [cited 2019; Available from: http://ki.se/medarbetare/program-4d.

160. Green, J.T., N., *Qualitative Methods for Health Research*. 3 ed. 2014, London: SAGE publications.

161. Graneheim, U.H. and B. Lundman, *Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness.* Nurse education today, 2004. 24(2): p. 105-112.

162. Hsieh, H.-F. and S.E. Shannon, *Three approaches to qualitative content analysis.* Qualitative health research, 2005. 15(9): p. 1277-1288.

163. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative research in psychology, 2006. 3(2): p. 77-101.

164. Korstjens, I. and A. Moser, *Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing.* European Journal of General Practice, 2018. 24(1): p. 120-124.

165. de Winter*, J.d., D. Dodou*, and P.A. Wieringa, *Exploratory factor analysis with small sample sizes.* Multivariate behavioral research, 2009. 44(2): p. 147-181.

166. Fayers, P.M. and D. Machin, *Multi-item scales*, in *Quality of Life The assessment, analysis and interpretation of patient-reported outcomes*. 2007, John Wiley and Sons. p. 123-124.

167. Fayers, P.M. and D. Machin, *Choosing and scoring questionnaires*, in *Quality of Life The assessment, analysis and interpretation of patient-reported outcomes*. 2007, John Wiley & Sons. p. 216.

168. Schwarz, P.E., et al., *Tools for predicting the risk of type 2 diabetes in daily practice.* Hormone and metabolic research, 2009. 41(02): p. 86-97.

169. Malterud, *Qualitative research: Standards challenges, and guidlines.* The Lancet, 2001. 358(9280): p. 483-488.

170. Fisher, R.J., *Social desirability bias and the validity of indirect questioning.* Journal of consumer research, 1993. 20(2): p. 303-315.

171. Harris, P.A., et al., *Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support.* Journal of biomedical informatics, 2009. 42(2): p. 377-381.

172. Sekhon, M., M. Cartwright, and J.J. Francis, *Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework.* BMC health services research, 2017. 17(1): p. 88.

173. Heale, R. and A. Twycross, *Validity and reliability in quantitative studies.* Evidence-based nursing, 2015. 18(3): p. 66-67.

174. Sachs, L., *Att leva med risk: fem kvinnor, gentester och kunskapens frukter.* . 1998: Gedin.

175. Fainzang, S., *Lying, secrecy and power within the doctor-patient relationship.* Anthropology & Medicine, 2002. 9(2): p. 117-133.

176. Eborall, H., et al., *Patients' experiences of screening for type 2 diabetes: prospective qualitative study embedded in the ADDITION (Cambridge) randomised controlled trial.* BMJ, 2007. 335(7618): p. 490.

177. Furst, T., et al., *Food choice: a conceptual model of the process.* Appetite, 1996. 26(3): p. 247-266.

178. Swartz, D.L., *The sociology of habit: The perspective of Pierre Bourdieu.* OTJR: Occupation, Participation and Health, 2002. 22(1_suppl): p. 61S-69S.

179. Association, A.D., *Screening for diabetes.* Diabetes care, 2002. 25(suppl 1): p. s21-s24.

180. Adriaanse, M., et al., *Screening for type 2 diabetes: an exploration of subjects' perceptions regarding diagnosis and procedure.* Diabetic Medicine, 2002. 19(5): p. 406-411.

181. van Dijk, W., et al., *Medicalisation and overdiagnosis: what society does to medicine.* International journal of health policy and management, 2016. 5(11): p. 619.

182. Brodersen, J., et al., *Overdiagnosis: what it is and what it isn't*. 2018, Royal Society of Medicine.

183. Strait, A., et al., *Acceptability of a multilevel intervention to improve blood pressure control among patients with chronic kidney disease in a public health care delivery system.* Clinical Kidney Journal, 2018. 11(4): p. 540-548.

184. Brokaw, S.M., et al., *Effectiveness of an adapted diabetes prevention program lifestyle intervention in older and younger adults.* Journal of the American Geriatrics Society, 2015. 63(6): p. 1067-1074.

185. Group, D.P.P.R., *Achieving weight and activity goals among diabetes prevention program lifestyle participants.* Obesity research, 2004. 12(9): p. 1426-1434.

186. Feldstein, A.C., et al., *Improved therapeutic monitoring with several interventions: a randomized trial.* Archives of Internal Medicine, 2006. 166(17): p. 1848-1854.

187. Bo, A., et al., *Early-onset type 2 diabetes: Age gradient in clinical and behavioural risk factors in 5115 persons with newly diagnosed type 2 diabetes—Results from the DD2 study.* Diabetes/metabolism research and reviews, 2018. 34(3): p. e2968.

188. Fisher, E.B., et al., *Peer support for self-management of diabetes improved outcomes in international settings.* Health affairs, 2012. 31(1): p. 130-139.

189. Pachucki, M.A., P.F. Jacques, and N.A. Christakis, *Social network concordance in food choice among spouses, friends, and siblings.* American journal of public health, 2011. 101(11): p. 2170-2177.

190. Whitehead, M. and G. Dahlgren, *Concepts and principles for tackling social inequities in health: Levelling up Part 1.* World Health Organization: Studies on social and economic determinants of population health, 2006. 2: p. 460-474.

191. Aweko, J., et al., *Patient and Provider Dilemmas of Type 2 Diabetes Self-Management: A Qualitative Study in Socioeconomically Disadvantaged Communities in Stockholm.* International Journal of Environmental Research and Public Health, 2018. 15(9).

192. Fritzell, J., M. Nermo, and O. Lundberg, *The impact of income: assessing the relationship between income and health in Sweden.* Scandinavian journal of public health, 2004. 32(1): p. 6-16.

193. Mackenbach, J.P., *The persistence of health inequalities in modern welfare states: the explanation of a paradox.* Social science & medicine, 2012. 75(4): p. 761-769.

194. Van de Mortel, T.F., *Faking it: social desirability response bias in self-report research.* Australian Journal of Advanced Nursing, The, 2008. 25(4): p. 40.

195. Schmier, J.K. and M.T. Halpern, *Patient recall and recall bias of health state and health status.* Expert review of pharmacoeconomics & outcomes research, 2004. 4(2): p. 159-163.

196. Stull, D.E., et al., *Optimal recall periods for patient-reported outcomes: challenges and potential solutions.* Current medical research and opinion, 2009. 25(4): p. 929-942.

197. Levine, L.J. and M.A. Safer, *Sources of bias in memory for emotions.* Current Directions in Psychological Science, 2002. 11(5): p. 169-173.

198. Agarwal, G., et al., *Choosing the most appropriate existing type 2 diabetes risk assessment tool for use in the Philippines: a case-control study with an urban Filipino population.* BMC public health, 2019. 19(1): p. 1169.

199. Revilla MA, S.W., Krosnick JA, *Choosing the Number of Categories in Agree-Disagree Scales.* Sociological Methods & Research, 2014. 43(1): p. 73-97.

200. Krosnick, J.A., *Survey research.* Annual Review of Psychology, 1999. 50: p. 537-567.

201. Saris, W., et al., *Comparing questions with agree/disagree response options to questions with construct-specific response options.* Survey Research Methods. 2010; 4 (1): 61-79. DOI: 10.18148/srm/2010. v4i1. 2682, 2010.